

An Overview
of
The Health Information Protection Act

NOTE:

This overview is presented for the convenience of reference only.
The Act and regulations should be consulted for all purposes of
interpretation.

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Introduction.

The Health Information Protection Act is designed to improve the privacy of people's health information while ensuring adequate sharing of information is possible to provide health services.

Development of the Act started in 1997. The process is summarized in the following points:

- In 1997, the Department distributed a consultation package to over 1200 stakeholder groups and individuals on key health information issues.
- Drafts of *The Health Information Protection Act* were widely distributed in December 1997, June 1998 and February 1999.
- A series of consultation sessions were held around the province in August and September 1998 to which more than 200 stakeholder groups were invited.
- Meetings and discussions with stakeholders and members of the public continued from October 1997 through to the Spring of 1999.
- The Act was introduced in the Legislature in April 1999. The Act received Royal Assent in May 1999.
- While preparing for implementation over the fall and winter 2000-2001, trustees identified several concerns with the Act that made application very difficult. The government heard the concerns of the major stakeholders and the decision was taken in spring 2001 to consider amendments to the Act to address these concerns, while still preserving the protection of personal health information.
- In October 2001 Saskatchewan Health distributed a formal consultation document on the amendments to all trustees or groups representing trustees and invited their comment.
- *The Health Information Protection Amendment Act, 2003* was introduced in the Legislature in May 2003. This Act received Royal Assent in June 2003.
- *The Health Information Protection Act* and *The Health Information Protection Amendment Act, 2003* are passed but do not come into force until they are proclaimed. Proclamation of these Acts is scheduled for September 1, 2003.
- The Regulations under *The Health Information Protection Act* will be developed and consulted on over the Fall and Winter of 2003-2004.

The Health Information Protection Act legislates rights of individuals and obligations of the "trustees" in the health system with respect to personal health information. This overview document explains how the various parts of the Act (including the amendments) work and how the Act will apply to significant issues of privacy and availability of personal health information.

The Act applies to personal health information in the health system in any form, including traditional paper records and emerging electronic records such as in the Saskatchewan Health Information Network.

The basic goal of the legislation is to protect privacy of personal health information, while at the same time ensuring that information is available as needed to provide services and to monitor, evaluate and improve the health system in Saskatchewan for the benefit of individuals and the province.

The Act is consistent with international standards for managing personal health information including the following:

- Personal health information is private and shall be dealt with in a manner that respects the individual.
- Personal health information should be primarily collected to benefit the individuals the information is about and wherever possible, the collection, use and disclosure of personal health information should occur with the consent of the individuals to whom it relates;
- Personal health information is essential to the provision of health services and it must be collected, used and disclosed only on a need-to-know basis;
- Individuals must be able to obtain access to records of their personal health information;
- Trustees of personal health information must protect the security, accuracy and integrity of personal health information, and they must be open and accountable for policies and practices with respect to personal health information.

Proclamation of *The Health Information Protection Act* and *The Health Information Protection Amendment Act, 2003* will occur on September 1, 2003.

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Parts of the Act explained.

Preamble

The Act begins with a statement of principles regarding personal health information. These principles are drawn from:

- Saskatchewan Health's Statement of Principles for health information;
- the Canadian Standards Association's Model Code for the Protection of Personal Information;
- the Canadian Medical Association's Health Information Privacy Code, and;
- other similar statements of principle.

The principles include statements about:

- privacy of personal health information;
- collection, use and disclosure for a purpose;
- the essential value of personal health information for the provision of services;
- and other internationally accepted principles.

Part I - Preliminary Matters

Part I can be viewed as housekeeping. It provides information necessary to understand the remainder of the Act. In particular it provides definitions of terms used in the Act and it states the scope of the Act (i.e., to whom and what it applies).

Of particular importance are the following:

- **Section 2 - Interpretations**
 - 2(c) – the definition of comprehensive health record.

The Act defines comprehensive health record as a record of an individual's personal health information that is created and controlled by Saskatchewan Health Information Network or any other person prescribed in the regulations under the Act (e.g. a computer company such as ISM, CGI, or EDS Canada) for the purpose of maintaining a comprehensive health history of an individual that would be available to trustees. This is the record to which section 8 of the Act applies. It is not the intent that this definition apply to more operational electronic health records that are

being created, for example, by regional health authorities, affiliates, and/or physicians within the regional health authority for the purpose of providing services to people seeking services with the health region.

- 2(j) – the definition of information management service provider.

The Act applies to individuals or organizations that process, store, archive or destroy records of a trustee containing personal health information or that provides information management or information technology services to a trustee with respect to records of the trustee containing personal health information. This includes a trustee that carries out any of these activities on behalf of another trustee, but does not include a trustee that carries out any of these activities on its own behalf.

- 2(m) – the definition of personal health information.

The Act will apply to personal health information, which is defined as information about an individual's physical or mental health and/or information gathered in the course of providing a health service. It includes information gathered to register individuals for a service and it includes the health services number on the health card.

Examples of personal health information include:

- a medical record held by a physician;
 - a patient record held by a hospital;
 - registration information held by the Department of Health to register individuals for insured services;
 - information about lab tests being performed for an individual;
 - records of prescriptions filled by a pharmacist.
- 2(t) – the definition of trustee.

The Act applies to individuals and corporations who are part of Saskatchewan's health system and have custody and control of personal health information. The Act calls them **trustees**, to reflect the fact that they hold personal health information "in trust" and must manage it with the best interests of the individual in mind.

The list of trustees includes:

- government institutions (e.g. Saskatchewan Health);
- regional health authorities and affiliates (this includes hospitals and all health facilities operated by a health region);
- special care homes;
- personal care homes;

- mental health facilities;
- health facilities licensed under *The Health Facilities Licensing Act*;
- laboratories;
- pharmacies;
- community clinics;
- Saskatchewan Cancer Foundation;
- ambulance operators;
- regulated health professions including:
 - chiropodists/podiatrists, chiropractors, dental assistants, dental hygienists, dental therapists, dentists, denturists, dental technicians/technologists, dietitians, licensed practical nurses, medical laboratory technologists, medical radiation technologists, occupational therapists, ophthalmic dispensers/opticians, optometrists, speech/language pathologists and audiologists, pharmacists, psychiatric nurses, physical therapists, physicians and surgeons, psychologists, registered nurses, naturopathic physicians, and osteopathic physicians;

** In situations where a health professional is employed by a trustee (for example, a regional health authority), the employer is considered the trustee.*

- individuals or organizations providing health services through an agreement with a trustee;
- health profession regulatory bodies.

- **Section 3 – Application of the Act**

In particular:

- The Act does not apply to statistical or de-identified information.
- The Act does not apply to records of an individual where the person has been dead more for than 30 years or to records over 120 years old.

- **Section 4 – Act prevails**

The Act prevails over all other Acts and regulations in regard to personal health information held by trustees, including *The Freedom of Information and Protection of Privacy Act* and *The Local Authority Freedom of Information and Protection of Privacy Act*.

The following are exempted from certain sections of the Act, in particular, those dealing with collection, use, disclosure and access:

- *The Adoption Act* and *The Child and Family Services Act* because of the sensitive nature of the information and to ensure that these important services for children can continue unencumbered by additional legislation.
- Section 16 of *The Cancer Foundation Act* to allow the Saskatchewan Cancer Agency to continue to require reports on incidents of cancer.
- *The Workers' Compensation Act, 1979* and Part VIII of *The Automobile Accident Insurance Act* to allow these legislated functions to continue.
- *The Public Disclosure Act* to enable public authorities to disclose information about dangerous criminals in accordance with that Act.
- *The Public Health Act* and *The Mental Health Services Act* because of the unique information needs of these sensitive issues.
- *The Vital Statistics Act, 1995* or any former *Vital Statistics Act* to allow these legislated functions to continue.

The privacy provisions of these Acts and *The Freedom of Information and Protection of Privacy Act* continue to apply to these exemptions from *The Health Information Protection Act*.

Part II – Rights of the Individual

Part II provides a list of rights that individuals in Saskatchewan have in regard to their own personal health information. These are important to ensure that individuals are involved in decisions about their personal health information. The complete list is summarized here.

- **Sections 5 and 7 – Consent required for use or disclosure, and Right to revoke consent**

The Act states that individuals have the right to consent to the use or disclosure of their personal health information by a trustee, except in limited circumstances prescribed in the Act. Consent is already deemed to exist in certain circumstances (see sections 26 and 27) primarily related to the provision of care.

The Act states that trustees can only use or disclose personal health information with consent of the individual or in accordance with provisions of the Act that allow for use or disclosure.

The Act also states that individuals have the right to revoke consent to the

collection, use or disclosure of their personal health information that is in the held by a trustee. The revocation of the consent does not have a retroactive effect. A trustee must take all reasonable steps to comply with a revocation of consent by the individual.

- **Section 6 – Consent**

Where consent is required by the Act, it must satisfy the rules in section 6. In particular it requires that consent:

- is for the purpose the information is required;
- is informed;
- is given voluntarily;
- is not obtained through misrepresentation, fraud or coercion.

Consent is already deemed to exist (subsection 27(4)) in limited circumstances primarily related to provision of direct care to the individual. In those instances, the requirements for consent do not need to be met.

- **Section 8 – Rights regarding comprehensive health records on SHIN**

This section gives individuals the right to prevent access to a comprehensive health record that is created and controlled by SHIN or by a person prescribed in the regulations under the Act. The comprehensive health record is a record of an individual's personal health information that is created and controlled by SHIN or any other prescribed person for the purpose of maintaining a comprehensive health history of an individual that would be available to trustees. The individual may require that their comprehensive health record not be disclosed to trustees by giving a written direction to SHIN or the prescribed person. Upon receipt of such a written direction, SHIN or the prescribed person must comply.

This section does not apply to other services that may be offered by SHIN, such as office automation (e.g. e-mail, spreadsheets, word processing), program specific applications, or other services not part of the comprehensive health record.

- **Section 9 – Right to be informed**

This section states that individuals have a right to be informed about the anticipated use and disclosure of their personal health information. The section requires trustees to take reasonable steps to inform individuals about anticipated use and disclosure of personal health information.

Informing individuals is an integral part of gaining consent for collection, use or disclosure. An individual must be informed before they can legitimately

grant consent.

The section also requires that trustees have policy and procedure to inform individuals about their rights under the Act, including the right to access information about herself or himself. Policy and procedure might require the placement of posters in offices or waiting rooms, the distribution of pamphlets and brochures, or oral information provided by the trustee.

- **Section 10 – Right to information about disclosures without consent**

A trustee must be able to inform an individual about disclosures of his or her personal health information made without the consent of that individual. This does not apply to disclosures where the consent is deemed to exist. Trustees must take reasonable steps to fulfil this obligation. It can be met by keeping a record of disclosures, but the requirement can also be met by means, such as having good policy and procedures that can be relied upon to demonstrate or explain when a disclosure has occurred.

- **Section 11 – Rights regarding production of the health services number**

Section 11 prevents an individual from being refused a good or service (other than health services) solely because the individual refuses to provide her or his Health Service Number. The Health Services Number or "Hospitalization Card" is often required for identification for any number of reasons. Under the Act, an individual can still use the card if she or he chooses, but cannot be denied a non-health service if they are specifically asked for the Health Services Number and refuse to provide the card or number.

Trustees in the health system will continue to be able to require the card.

- **Section 12 – Right to access by individuals**

Section 12 states that individuals have the right to access their own personal health information held by trustees. The details are provided in Part V of the Act.

- **Section 13 – Right to request amendment**

If an individual reviews his or her record and disagrees with something in that record, that individual has the right to request that the record be amended. Although the Act prevents existing information from being destroyed, a trustee must add a notation to the file noting the request. The details of this right are provided in Part V of the Act.

- **Section 14 – Right to review or appeal**

Individuals have the right to request a review by the Information and Privacy Commissioner of actions or decisions of a trustee regarding their personal health information. There is also the right to appeal to a court. The details of these rights are provided in Parts VI and VII of the Act.

- **Section 15 – Right to designate**

An individual may designate another person to act on their behalf.

Part III – Duty of Trustees to Protect Personal Health Information

Trustees that collect and maintain personal health information have certain obligations to protect that information. Part III of the Act legislates a number of duties that trustees have to protect the information. The most significant ones are summarized here.

- **Section 16 – Duty to protect**

The Health Information Protection Act requires that trustees take reasonable steps to protect personal health information in their care. For example, in a computer system a trustee will need to ensure that industry standards for security and integrity are met or exceeded. The Act does not dictate what steps must be taken because standards change rapidly and any specifics in the Act might quickly become obsolete. Instead, the Act requires trustees to be reasonably up-to-date with security provisions for all types of information.

- **Section 17 – Retention and destruction policy**

The Act requires trustees to have policy in place regarding how long personal health information must be retained.

A trustee must also ensure that if records are eligible for disposal that they are disposed of securely.

The section also requires trustees take steps to ensure that changes in technology will not render information inaccessible during the period of time it is still required.

Saskatchewan Health will work with trustees to develop regulations setting minimum retention periods for various types of records of personal health information. The regulations will consider such things as continuing treatment, legal and fiscal requirements, family and genetic histories, research

needs, and privacy concerns. How long the record must be retained will reflect these various needs.

- **Section 18 – Information management service provider**

An information management service provider (IMSP) is an individual, an organization or a company that processes, stores, archives, destroys or combines personal health information on behalf of a trustee.

An IMSP can provide information management or information technology services to a trustee, but must act in accordance with directions provided by the trustee.

The Saskatchewan Health Information Network (SHIN) is an information management service provider. Other IMSPs may include, for example, a records warehouse, an archive or a data processing company. Section 18 describes how the relationship between a trustee and an information management service provider will work.

The following points are significant:

- The Act recognizes that trustees sometimes use the services of others to store data, manage records, or otherwise provide services to the trustee. The Act refers to these individuals and organizations as information management service providers.
- The Act enables trustees to use IMSPs provided written agreements are in place to ensure that all the obligations and responsibilities of the trustee are met.
- The trustee is still responsible for ensuring all the rights of the individuals are respected, including the need for consent for most use or disclosure of personal health information (even on a network such as SHIN).
- The IMSP must provide adequate security and protection for the information it manages on behalf of a trustee.
- The IMSP cannot make any decision about the information. The IMSP must follow the direction of the trustee who is bound by the Act.
- The agreements ensure the personal health information provided to an IMSP will not be treated differently from the personal health information in the files of the trustee. For example, through the agreements a physician will retain the same degree of control over an electronic health record on SHIN as he or she has over paper records in a locked file cabinet in the office.

Section 18, combined with other parts of the Act, will ensure that individual health records will only be accessed by those who need-to-know. Furthermore, even with a recognized need-to-know, the trustee can only access parts of a record required for a service. The legislation prevents "surfing" or scrolling of records by people that have access to an electronic system.

- **Section 18.1 – Defining, creating and providing access to a comprehensive health record**

As described above, section 8 gives individuals the right to prevent access to a comprehensive health record that is created and controlled by the Saskatchewan Health Information Network or by a person prescribed in the regulations under the Act. This section defines what a comprehensive health record is and how such a record is created. It also sets out the rules for accessing those records.

A comprehensive health record with respect to an individual consists of records containing the individual's personal health information from one trustee which are then combined with records containing the individual's personal health information from another trustee(s). This comprehensive health record is created for the purposes of compiling a complete health history of the individual and providing access to that history to any trustee. The comprehensive health record must be stored and controlled by the Saskatchewan Health Information Network or by the prescribed person that created it.

Comprehensive health records may be shared but only if authorized by each trustee whose records were used to compile the comprehensive health record and either the individual has provided written consent authorizing the trustee to have access or if subsections 27(2) or 27(4) of the Act permits it.

It should also be noted that it is not the intent that this section apply to more operational electronic health records that are being created, for example, by regional health authorities, affiliates, and/or physicians within the regional health authority for the purpose of providing services to people seeking services with the health region.

- **Section 20 – Duty where one trustee discloses to another**

This section clarifies what happens when a trustee discloses information to another trustee. If the second trustee records the information, then she becomes responsible for the information in that record. The trustee who disclosed the information is still responsible for the information they have in their records. Although the information exists in two places, it is part of two

separate records and must be managed accordingly.

- **Section 22 – Continuing obligations of trustees**

The Act requires that if a trustee ceases to be a trustee (e.g. retires or leaves the province), the personal health information must still be cared for in accordance with the Act.

For example, if a pharmacy goes out of business, the operator of the pharmacy continues to have obligations of a trustee until one of the following happens:

- The legal retention period defined under *The Health Information Protection Act* is satisfied and the information is safely destroyed.
- The personal health information is transferred to another trustee or information manager in accordance with the Act.

Part IV – Limits on Collection, Use and Disclosure of Personal Health Information by Trustees

Part IV of *The Health Information Protection Act* provides the rules for collection, use and disclosure of personal health information. The Part:

- requires that all collection, use or disclosure of personal health information must only be on a need-to-know basis;
 - emphasizes the need for consent prior to using or disclosing personal health information except in limited circumstances, including where consent is deemed to exist within a “circle of care”;
 - ensures that information is used for legitimate health services to benefit the patient and that some of the information is available to support the public health system;
 - provides rules that protect personal health information while ensuring sufficient sharing to allow the health system to function.
- **Section 23 – Collection, use and disclosure on need-to-know basis**

The section requires trustees to collect, use or disclose the minimum personal health information required for a particular purpose. Further, trustees must use or disclose de-identified information instead of identifiable personal health information, if it will serve the purpose. In other words, if a trustee needs information about a blood test, then they can only access the information related to the test, not the rest of a personal health record.

All sections of the Act dealing with collection, use or disclosure are subject to

this provision.

- **Section 24 – Restrictions on Collection**

This section intends to limit the collection of personal health information. The primary purpose for collecting personal health information must be for the benefit of the individual. Secondary purposes are allowed if the purposes are consistent with the reasons that a trustee may disclose information in sections 27, 28, or 29.

One of the principles of information management for personal information is to collect only what is needed. Collecting beyond that may constitute an invasion of privacy and result in the pooling of personal information for no particular reason. This section will limit that type of activity.

- **Section 25 – Manner of collection**

It is preferable to collect personal health information directly from the individual. *The Health Information Protection Act* reflects that preference.

However, secondary collection of information is often required. This section allows secondary collection to occur in limited circumstances.

- **Section 26 – Restrictions on use**

Section 26 limits what internal use trustees can make of personal health information.

Currently, professional ethics and the policy of trustees limit the use of personal health information -- these limits will continue to apply. The section places additional controls on the use of personal health information by trustees, thereby adding privacy to personal health information.

In particular:

- The section identifies those purposes where trustees can use personal health information – primarily providing health services – without reference to consent. However, individuals still have the ability to limit what information is provided at the time of collection. Furthermore, the trustee must have policies and procedures limiting use to a “need-to-know” basis (section 23) and must otherwise comply with the Act.
- The section requires consent for use of personal health information not otherwise provided for in the Act.
- The section prevents an employer from using an employee's personal

health information for employment purposes without first getting consent.

- The section requires trustees to limit use of information to those employees who have a need to know.
- **Section 27 – Disclosure**

Disclosing personal health information is a sensitive issue. It is often essential to facilitate the provision of a health service. For example, a physician must disclose some personal health information in order to refer a patient to a specialist or to arrange for needed surgery. Yet disclosing personal health information also means revealing very private information about an individual to another person. Because this impacts on the privacy of the individual, the Act creates strict rules for disclosing personal health information.

For the specific purposes of providing health services to an individual, the Act creates a patient-centred, “circle of care” where information is appropriately shared for the provision of health services to individuals. The Act recognizes that consent is deemed to exist for disclosing personal health information within the “circle of care”. The Act also creates strong “walls” of consent and security around the “circle of care”. For example, if an individual reveals personal information to hospital staff as part of the admittance procedure, consent is deemed to exist for the disclosure of the individual’s personal health information for the purposes of the visit to the hospital. Any use or disclosure beyond that requires express consent or must be an exception identified in the Act.

There are a number of circumstances where disclosing personal health information without consent may be necessary and reasonable. For example, if a trustee receives a subpoena to disclose personal health information to a court of law, consent is not an issue - the trustee must comply. The Act provides limited circumstances where information can be disclosed without consent.

- **Section 28 – Disclosure of registration information**

Registration information is primarily demographic information (such as name, birth date, and gender) that is gathered by a trustee when registering an individual for a service. The consultation on the protection of personal health information revealed strong support for sharing registration information by the Department of Health with regional health authorities and with other government departments to facilitate the provision of health services and to cut down on administrative overhead.

Section 28 supports this by providing for the sharing of registration information in a limited number of circumstances. In each instance the

disclosure is subject to Section 23, which requires a trustee to disclose only de-identified information if it will serve the purpose or, if not, to disclose only the minimum identifiable personal health information required.

- **Section 29 – Use and disclosure for research**

Personal health information can be an indispensable resource when conducting research to prevent disease or find new cures or treatments. The public benefits from good, ethical research can be significant, however, it cannot happen without proper steps to protect the privacy of the individuals the information is about. Section 29 sets out the rules under which trustees can use or disclose personal health information for research. In particular, it requires all research proposals to be reviewed by a recognized research ethics committee and, wherever practicable, the consent of the individual received prior to disclosure. As well, Section 23 would apply so that a trustee can only disclose de-identified information if it will serve the purpose or, if not, to disclose only the minimum identifiable personal health information required for the research project.

- **Section 30 – Use or disclosure prohibited**

If a person obtains personal health information in violation of the Act, they are prohibited from using that personal health information. If they do, they are in violation of the Act and are subject to fines or imprisonment. For example, if an individual steals personal health information and sells it in violation of the Act, they can be charged with an offence and are subject to a fine of up to \$50,000 (or \$500,000 if the crime is by a corporation). Any third party that knowingly uses the stolen information would also be in violation of the Act. For example, if the information were published in a book or a newspaper, the publisher of that book or newspaper could also be violating the Act.

Part V – Access of Individuals to Personal Health Information

Part V ensures that an individual will receive access to her or his personal health information held by a trustee. Access can happen in two ways:

1. An individual can simply make an oral request to see his or her record and the trustee can comply. If this happens, the remainder of this Part on access does not apply. This is often how individuals access their health information and is facilitated by Section 33.
2. If an individual cannot get access by an oral request, he or she may start a more formal process by making the request in writing. Sections 32, 34-40 lay out the process for making and responding to a written request.

In particular:

- **Section 36 – Response to written request**

In responding to a written request a trustee must either:

- Make the information available to the individual.
- Inform the individual that the information does not exist.
- If the trustee does not have the information, transfer the request to a trustee that does.
- Refuse access according to the limited number of reasons described in Section 38.

- **Section 38 – Refusing access**

An individual has the right to access information about him or herself. However, depending on the circumstances, a record may contain information about another person. Section 38 gives the trustee the ability to refuse access to certain information that includes:

- Information that could cause harm to any individual.
- Personal health information about another person.
- Third party information supplied in confidence.
- Procedures and activities of professional investigations or reviews that are by definition not about the applicant but may be about the applicant's provider.
- Information that, if disclosed, could interfere with a lawful investigation or with enforcing an Act or regulation.

Where a trustee refuses access in accordance with these exceptions, they must grant access to whatever portion of the record is actually the personal health information of the applicant.

- **Section 39 – Fee**

In some cases, providing access to large amounts of personal health information may result in expenditures for the trustee. For example, it may be necessary to photocopy a large volume of records in order to provide the individual with access. The section allows a trustee to charge a fee if they believe it is appropriate. Regulations may be developed to establish fees.

- **Section 40 – Right of amendment**

Once an individual gets access to her or his personal health information held by a trustee, they might identify some information which they would like changed. An individual may make a request for an amendment and a trustee

can either make the change or simply add an addendum to the record noting a difference of opinion.

Part VI – Review and Appeal and Part VII – Commissioner

Parts VI and VII establish the right of an individual to appeal to an independent third party actions or decisions of trustees regarding access to personal health information, and to appeal regarding perceived violations of the Act.

The existing office of the Information and Privacy Commissioner (established under *The Freedom of Information and Protection of Privacy Act*) is the independent third party.

The Act ensures that a person can request a review by the Commissioner if:

1. The person is not satisfied with a decision by a trustee regarding access to personal health information.
2. The person requests an amendment to personal health information and the amendment is not made in accordance with the Act.
3. The person believes there has been a contravention of the Act.
4. The person believes a fee charged by a trustee for access to personal health information will cause undue hardship.

The Commissioner may choose to review the matter and make a recommendation to the trustee. The Commissioner may also recommend other actions such as mediation.

The Act also allows for an individual to appeal to a court once the review of the Commissioner is complete, if the individual is still not satisfied.

Part VIII – General

Part VIII addresses a number of issues necessary to complete the intent of the Act. Significant sections include:

- **Section 56 – Exercise of rights by other persons**

An individual may not always be in a position to understand and exercise their rights under this Act. Section 56 provides for other individuals to be able to act on behalf of such an individual.

The section provides for rights to be exercised by:

- A personal representative if an individual is deceased.
 - A personal guardian appointed by the individual.
 - An individual less than 18 years of age if they understand the consequences.
 - A legal custodian of an individual less than 18 years of age, if it does not constitute an unreasonable invasion of privacy.
 - A person appointed by an individual under *The Health Care Directives and Substitute Health Care Decision Makers Act* to make health care decisions on behalf of the individual.
 - A person designated by the Minister of Social Services for individuals receiving services pursuant to *The Residential Services Act* or *The Rehabilitation Act*, if the person receiving services is not capable of making a decision.
 - Any person with written authorization of the individual.
- **Section 61 – Proceedings prohibited**

This section protects people acting in good faith from prosecution under the law. In other words, if a trustee believes he or she is in compliance with the Act, then they are acting in good faith. Use or disclosures not made in good faith and which knowingly contravene the Act, are considered violations.

- **Section 63 – Regulations**

This section gives the government the ability to create the regulations referred to throughout the Act. This section also places limits on a government's ability to make certain regulations by requiring significant consultations before they can proceed.

- **Section 64 – Offences**

Section 64 describes an offence under the Act and provides for the following penalties:

1. For individuals found guilty of an offence (including the directors, officers or agents of a corporation), a judge may order payment of a fine of up to \$50,000 per offence or sentence the person to up to one-year imprisonment, or both.
2. For a corporation found guilty of an offence, a judge may order payment of a fine of up to \$500,000 per offence.

Part IX – Transitional, Consequential Amendments and Coming into Force

- **Section 65 – Transitional**

This section is included in case some trustees are not able to comply with parts of the Act immediately upon proclamation. It allows for specified activities of a trustee to receive a limited exemption from the Act. This section will be used very sparingly (and preferably not at all). It requires a decision of Cabinet and it must be time limited. Finally, it cannot have any significant impact on the interests of the individuals whose personal health information may be affected.

- **Sections 66 to 70 – Consequential amendments**

Sections 66 to 70 amend several existing statutes in order to avoid conflict with this Act.

- **Section 71 – Coming into force**

This final section states that the Act only comes into force upon proclamation.

Frequently asked questions.

1. *What is the purpose of the Act?*

The Health Information Protection Act legislates rights of individuals and obligations of "trustees" in the health system with respect to personal health information. It applies to personal health information in the health system in any form, including paper records, on microfilm, on x-ray film, and electronic records in the Saskatchewan Health Information Network.

The Act identifies a series of rights that individuals have in regard to their personal health information -- for example, the right to consent to the use and disclosure of their personal health information unless the Act provides otherwise.

After identifying those rights, the Act establishes a legal framework for the handling of personal health information to ensure that the rights are respected.

The basic goal of the legislation is to provide individuals with increased protection of privacy of personal health information, while at the same time ensuring that information is available as needed to provide services and to monitor, evaluate and improve the health system in Saskatchewan for the benefit of individuals and the province.

2. *Who must abide by the Act?*

Simply put, *The Health Information Protection Act* applies to a group of stakeholders throughout the health system and government referred to as "trustees" in the Act. The Act calls them **trustees**, to reflect the fact that the health system holds personal health information in trust and must manage it with the best interests of the individual in mind. Trustees include (for example): regional health authorities and affiliates; members of regulated health professions; government institutions. For the complete list, see Part I above entitled "Parts of the Act Explained".

The law applies to any personal health information held by trustees; so all trustees must be able to comply with the law for the collection, use storage, disclosure and maintenance of personal health information.

The Act does not apply to organizations outside of government and the health sector that happen to collect personal health information, for example, retailers life insurance companies.

3. What information will be covered by the Act?

The Health Information Protection Act applies to personal health information, which is any information about an individual's physical or mental health, or information gathered in the course of providing a health service. It includes information gathered to register individuals for a service and it includes the health services number on the health card. The Act applies to all personal health information in the custody or control of trustees.

The Act applies to personal health information on computers, in paper files, on microfilm, on x-ray film, and anywhere the personal health information is stored by a trustee.

Examples of personal health information include:

- a medical record held by a physician,
- a patient record held by a hospital,
- registration information held by the Department of Health to register individuals for insured services,
- information about lab tests being performed for an individual,
- records of prescriptions filled by a pharmacist.

4. How does the Act work?

The Health Information Protection Act legislates rights of individuals and obligations of "trustees" in the health system with respect to personal health information. It applies to personal health information in the health system in any form, including paper records, on microfilm, on x-ray film, and electronic records in the Saskatchewan Health Information Network.

The Act identifies a series of rights that individuals have in regard to their personal health information -- for example, the right to be informed about why their personal health information is being collected and how it will be used or disclosed.

After identifying those rights, the Act establishes a legal framework for the handling of personal health information to ensure that the rights are respected. The Act legislates a number of duties that trustees have to protect the personal health information they collect.

The remainder of the Act sets out the way in which individuals and trustees collectively live up to the rights and duties described above. For example, Part IV addresses the key issues regarding acceptable circumstances for the collection, use and disclosure of personal health information including the requirement for consent in many instances.

5. How does the Act protect against improper disclosure of my personal health information?

The Health Information Protection Act protects privacy by placing limits on the use and disclosure of personal health information. In particular:

- Information can only be used or disclosed by a trustee with the consent of the individual or for purposes permitted in the Act.
- A trustee must use information in a de-identified format if possible.
- A trustee can only collect, use or disclose information on a need-to-know basis.

Disclosure with consent or for limited reasons permitted in the Act

Disclosing personal health information is a sensitive issue. It is often essential to facilitate the provision of a health service. For example, a physician must disclose some personal health information in order to refer a patient to a specialist or to arrange for needed surgery. Yet disclosing personal health information also means revealing very private information about an individual to another person. Because this impacts on the privacy of the individual, the Act creates strict rules for disclosing personal health information.

For the specific purposes of providing health services to an individual, the Act creates a patient-centred, “circle of care” where information is appropriately shared for the provision of health services to individuals. The Act recognizes that consent is deemed to exist for sharing personal health information within the “circle of care”. The Act also creates strong “walls” of consent and security around the “circle of care”. For example, if an individual reveals personal information to hospital staff as part of the admittance procedure, consent is deemed to exist for the use and disclosure of the individual’s personal health information for the purposes of the visit to the hospital. Any use or disclosure beyond that requires express consent or must be an exception identified in the Act.

The Act provides limited circumstances where personal health information can be disclosed without consent. For example, if a trustee receives a subpoena to disclose personal health information to a court of law, consent is not an issue – the trustee must comply.

For any other purpose, the Act clearly states that an expressed consent must be obtained.

In all cases, the Act requires that trustees limit the information used or disclosed as much as possible and that they use or disclose non-identifiable information if

possible.

Need-to-know

The Act ensures that personal health information can only be collected, used or disclosed when there is a need-to-know. Trustees must have policies and procedures in place that limit the collection, use and disclosure of personal health information to a need-to-know basis. Collection, use (or access to) or disclosure of other personal health information is not acceptable. For example, for the Department of Health to issue payment to a physician for a service provided to a patient, the Department will only receive the minimum information required to know what to pay. The Department will not have access to any other information contained in the records of the physician about that service.

6. What are my individual rights under the Act?

The Act is about the rights of individuals. Part II entitled "Rights of the Individual" sets out quite clearly what those rights are. Through the protection offered by the rest of the Act, an individual's rights and interests in the personal health information are upheld.

Rights specifically identified in the Act include:

- The *right to consent* to use and disclosure of personal health information except where consent is deemed to exist or where otherwise authorized by the Act.
- The *right to revoke consent* to the use or disclosure of personal health information.
- The *right to prevent access to a comprehensive health record of one's personal health information that is created and controlled by SHIN or by a prescribed person.*
- The *right to be informed* by trustees about anticipated use and disclosure of personal health information.
- The *right to be informed about disclosures* without consent of personal health information.
- The *right to refuse to provide the Health Services Number* as identification for a non-health service.
- The *right to access personal health information about oneself* held in the records of any trustee.
- The *right to request amendments* to records of personal health information.
- The *right to request a review* by the Information and Privacy Commissioner about a decision by a trustee about access or any perceived violation of the Act by a trustee.
- The *right to appeal to a court* the decisions of a trustee regarding recommendations of the Commissioner.

- The *right to designate another person to make decisions* about personal health information for the individual.

7. What are the responsibilities of a trustee under the Act?

The Health Information Protection Act places a duty on trustees to protect personal health information and to respect the rights of individuals identified in the Act.

The Act puts into legislation many of the current practices of trustees to ensure confidentiality and privacy, and it adds some others. Trustees must comply with all the rules regarding collection, use, disclosure, storage, retention and destruction of records containing personal health information.

Individuals have rights and trustees have an obligation to respect those rights. Among other things a trustee must:

- ***Obtain consent*** to use or disclose personal health information where required by the Act (i.e., unless the Act deems consent to exist in circumstances where use or disclosure is permitted without consent), except in circumstances described in the Act.
- ***Make sure that there are written policies and procedures*** to ensure proper use and disclosure of personal health information within the circle of care – i.e., where consent is deemed to exist for the use and disclosure of personal health information to provide individuals with a health service.
- ***Ensure consent is informed***, voluntary and that it relates to the purpose the information is required.
- ***Inform the individual*** about intended use and disclosure of the information.

In addition, trustees must provide proper care and attention to the information they gather and maintain about individuals. For example, trustees have a duty to:

- ***Protect the integrity, accuracy and confidentiality*** of personal health information.
- ***Provide security*** for personal health information.
- Have ***policy and procedure about retention and destruction*** of personal health information.
- Enter into ***binding legal agreements with information management service providers*** (e.g. information technology service providers such as SHIN or ISM), before using the services of the IMSP, to ensure that the information is kept private and to ensure that the IMSP can only do as directed by the trustee.

Respecting the privacy of individuals also extends to the day-to-day activities of trustees and the collection, use and disclosure of personal health information. In

particular a trustee must:

- Only collect, use and disclose personal health information on a *need-to-know* basis.
- Only collect *information primarily for the benefit of the individual* the information is about, or for limited purposes acceptable under the Act.
- *Collect from the individual* whenever possible and practical.
- *Only use* personal health information in accordance with the Act.
- *Only disclose* personal health information in accordance with the Act.

8. How is access to my personal health information by others limited?

The Act limits access to personal health information in two ways. First, with very few exceptions, access can only be gained with the consent (expressed or deemed) of the individual and when the trustee holding the information agrees. Second, a trustee can only access information if they have a need-to-know for a legitimate purpose.

9. Will this Act change the way my personal health information is protected?

The Act builds upon existing practice to improve the protection of personal health information. For example, the Act:

- *Standardizes information practices* in the health system.
- Extends *regulation of information practices* in parts of the health system *not previously controlled*.
- Gives individuals the *right to access* their own health information anywhere in the health system.
- Adds legal *limits to accessing* personal health information. From now on, even within the walls of a single institution, only those who need to know can access the information.
- Places limits on the *collection of the Health Services Number*.
- Stipulates that *employers cannot access personal health information* of employees for purposes of employment without consent of the employee.
- Creates an *independent third party* to mediate disputes over treatment of personal health information.
- Requires that trustees take appropriate steps to *protect against threats* to security or integrity of the information, loss of the information or unauthorized access to or use, disclosure or modification of the personal health information.

- Creates rules to ensure that *information on the Saskatchewan Health Information Network is used and accessed only with a trustee's or an individual's permission*. There will be no "surfing" of the network.
- Establishes *very serious penalties* for abuse of personal health information.

10. How will the Act protect privacy of personal health information on the Saskatchewan Health Information Network?

Personal health information on the Saskatchewan Health Information Network (SHIN) will be protected in a number of ways.

1. With few exceptions (such as within the "circle of care" where consent is deemed to exist), consent of the individual will be required prior to disclosure of personal health information.
2. The Saskatchewan Health Information Network will have to follow the directions of trustees - like the family doctor - regarding the sharing of information.
3. Only information that a trustee deems appropriate will be placed on the network.
4. Individuals have the right to prevent access to a comprehensive health record of their personal health information that is created and controlled by SHIN or by a prescribed person.
5. The trustee will require SHIN to limit access by other trustees.
6. The trustee will require SHIN to have proper security in place to protect the information.
7. Trustees will only have access to information appropriate to their needs.
8. Trustees will only have access to information that the original trustee agrees can be accessed by them.
9. Agreements must be in place regarding all aspects of information management on the network.
10. Nothing in the Act requires a trustee or an individual to put information on the Saskatchewan Health Information Network.

The Health Information Protection Act will ensure that decisions about sharing information on the Saskatchewan Health Information Network begin with the individuals the information is about. Trustees will be responsible for ensuring that all professional, ethical and legal obligations for use or disclosure of information are met prior to information being shared on SHIN. These conditions will be reflected in agreements between SHIN and the trustees allowing the sharing of information when and where it is needed.

11. Can personal health information be disclosed for research?

Personal health information can be an indispensable resource when conducting research to prevent disease or find new cures or treatments. The public benefits from good, ethical research can be significant; however, it cannot happen without proper steps to protect the privacy of the individuals it is about. The Act sets out rules under which trustees can use or disclose personal health information for research. In particular, it requires all research proposals to be reviewed by a recognized research ethics committee and, wherever practicable, the consent of the individual received prior to disclosure. As well the Act requires that the trustee can only disclose de-identified information if it will serve the purpose or, if not, to disclose only the minimum identifiable personal health information required for the research project.

12. Can individuals access their own records?

The Act legislates an individual's right to access information about themselves held by any trustee in the health system. It also provides rules for amendments to that information contained in the records of a trustee.

13. What is the role of the Information and Privacy Commissioner?

The Act names the existing office of the Information and Privacy Commissioner to handle complaints and monitor enforcement of the legislation.

14. What are the penalties for violations of the Act?

The government is serious about protecting the privacy of individuals. Therefore, the penalties for violating this Act that is designed to protect personal health information are high. If a person is found guilty of an offence, they can be fined up to \$50,000 or sentenced to up to one year in jail. A corporation can be fined up to \$500,000 and its officers and directors subject to a \$50,000 fine or one year in jail. The Act also contains a good faith clause, so that if a trustee acts in the belief that they are abiding by the law, they will not be prosecuted.

15. Can trustees sell or market personal health information?

The sale or marketing of personal health information is not an acceptable reason for use or disclosure under the Act. The Act does not apply to statistical or aggregate data that cannot be identified with an individual. Personal health information that would identify an individual could not be sold or marketed by a trustee without the individual's express consent.