Saskatchewan Cancer Agency

DIVISION: Quality and Information Management

POLICY #: PRI-0202

DEPARTMENT: Quality, Safety, and Risk

ISSUE DATE: December 19, 2011

CATEGORY: Privacy

REVISED DATE:

POLICY TITLE: Collection, Use, and Disclosure of Personal/Health Information for Research Purposes

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Policy Statement
The Saskatchewan Cancer Agency (SCA) collects, uses, and discloses personal/health information for research purposes pursuant to the *Health Information Protection Act* (HIPA) and the *Local Authority Freedom of Information and Protection of Privacy Act* (LA FOIP).

Purpose
To outline a framework to support compliance with HIPA and LA FOIP when the Agency collects, uses, and discloses personal/health information for research purposes.

Application
This policy applies to all staff, students, and volunteers of the SCA.

Authority
CEO

Information
Privacy Officer

Approved by: _____ Signature	Date: Dec 19, 2011

Definitions

Approved Research Ethics Committee
Ethics committee approved by the Minister (member of Saskatchewan's Executive Council who is assigned to administrate HIPA).

1.0 General Principles

When the Agency collects, uses, and discloses personal/health information for research purposes, it shall comply with the following:

1.1 Collection

The Agency shall collect personal/health information in accordance with HIPA and LA FOIP, when the Agency collects personal/health information for research purposes (See: *PRI-0201-Collection of Personal/Health Information*).

1.2 Use of and Disclosure of Personal/Health Information for Research Purposes with Consent

The Agency shall use and disclose an individual's personal/health information for research purposes with the express consent of that individual. When the Agency uses and discloses an individual's personal/health information with express consent:

(a) the project must be in the public interest;
(b) an approved research ethics committee must approve the project;
(c) the Agency must enter into an agreement with the person who is to receive the information regardless of whether or not the person who is to receive the information is an employee of the Agency; and
(d) the Agency shall only provide the personal/health information which is necessary to meet the research purpose.

1.2.1 Research Agreement

The Agreement with the person who is receiving the personal/health information from the Agency shall require the person to agree:

(a) to comply with applicable privacy laws;
(b) to use the personal/health information only for the research purpose, not to use or disclose the information for a secondary purpose, and that any other use or disclosure of the personal health information is considered a breach pursuant to HIPA and LA FOIP;
(c) to keep the personal/health information confidential;
(d) not to disclose the personal/health information unless required by law, and notify the Agency if the researcher is required to disclose the information by law;
(e) to de-identify and aggregate any identifiable data extracted from the information provided to the researcher;
(f) not to disclose any identifiable data extracted from the information;
(g) to restrict access to the identifiable information to only those

employees of the researcher that require access to the information to perform activities associated with the research purpose and to provide employees with the necessary training to ensure that employees maintain the security and confidentiality of the information;

(h) to store information securely, safeguard information during data extraction and, at all times, maintain the security and confidentiality of the information;

(i) to either:

  (i) destroy the personal/health information and furnish the Agency with written proof that the personal/health information has been destroyed; or

  (ii) to immediately and securely return the personal/health information to the Agency in the following circumstances:

    (A) when the personal health information required to complete the research purpose has been obtained and has been de-identified and/or aggregated as necessary to fulfil the research purpose;

    (B) when the agency provides notice to the individual; or

    (C) when the agreement terminates;

(j) to cooperate with, and assist in, any investigations of a privacy complaint;

(k) to cooperate and assist with access to information requests;

(l) to immediately notify the Agency in the event of a suspected or confirmed breach of terms, including privacy breaches, and to take steps to mitigate any harmful effect resulting from the breach, in consultation and at the direction of the Agency;

(m) to allow the Agency to audit the Researcher's compliance with the terms of the agreement, and at the request of the Agency, to provide evidence of compliance with the agreement to the Agency; and

(n) to acknowledge that the agreement is binding, and is binding upon all successors to the researcher, and enforceable by the Agency.

1.3 Use of and Disclosure of Personal/Health Information for Research Purposes without Consent

The Agency may use and disclose personal/health information for research purposes without consent if obtaining consent is not practical as long as the following conditions are met:

(a) the research purpose cannot reasonably be accomplished using de-identified personal/health information or other information;

(b) reasonable steps are taken to protect the privacy of the subject individual by removing all personal/health information that is not required for the purposes of research;

(c) in the opinion of the research ethics committee, the potential benefits of

the research project clearly outweigh the potential risk to privacy of the subject individual; and

(d) all the conditions as stated in 1.1 – 1.2.1 have been met.

1.4 Information Management Service Provider

If the research project requires the Agency to contract an Information Management Service Provider to perform any part of the research project, the Agency shall contract services pursuant to HIPA (See: *PRI-0208-Contracting Information Management Service Providers*).

1.5 Obtaining Consent for Use and Disclosure for the Purpose of Research

Consent for the use and disclosure of personal/health information for research purposes shall be obtained in accordance with HIPA and LA FOIP (See: *PRI-0300-Consent for the Collection, Use, and Disclosure of Personal/Health Information*).

1.6 Risk Management

To evaluate the risks to personal privacy associated with a research project, the Agency shall perform a privacy impact assessment when necessary (See: *PRI-0203-Privacy Impact Assessments*).

Related Policies

PRI-0100 to *PRI-0800*

References

Cancer Agency Act
Health Information Protection Act and Regulations
Local Authority Freedom of Information and Protection of Privacy Act and Regulations
Provincial Chief Information Office Health Privacy Toolkit