



# PRIVACY POLICY

## Our Commitment

The Hereditary Breast and Ovarian Cancer Society ("HBOC Society") understands the importance of personal privacy and values the privacy of our members. The HBOC Society acknowledges the sensitivity of personal information, particularly the sensitivity of personal health information. Therefore, we have adopted this privacy policy to reflect and shape the practices of our organization.

The objective of this privacy policy is to adopt responsible information practices. This policy will be reviewed periodically in order to ensure its timeliness and relevance.

## Overview

This Privacy Policy requires that the HBOC Society limit the use and disclosure of personal information. Personal medical information will not be used or disclosed without the express prior consent of the individual from whom the information was collected.

## Introduction

This Privacy Policy is modeled on the Canadian Standards Association's **Model Code for the Protection of Personal Information: A National Standard of Canada**, CAN/CSA-Q830-96.

## Summary of Principles

This Privacy Policy adopts the ten principles of the CSA Model Code, namely:

### 1. Accountability

An organization is responsible for personal information under its control and shall designate an individual or individuals who are accountable for the organization's compliance with the following principles.

### 2. Identifying Purposes

The purposes for which personal information is collected shall be identified by the organization at or before the time the information is collected.

### 3. Consent

The knowledge and consent of the individual are required for the collection, use, or disclosure of personal information, except where inappropriate.

### 4. Limiting Collection

The collection of personal information shall be limited to that which is necessary for the purposes identified by the organization. Information shall be collected by fair and lawful means.

### 5. Limiting Use, Disclosure, and Retention

Personal information shall not be used or disclosed for purposes other than those for which it was collected, except with the consent of the individual or as required by law. Personal information shall be retained only as long as necessary for the fulfilment of those purposes.

### 6. Accuracy

Personal information shall be as accurate, complete, and up-to-date as is necessary for the purposes for which it is to be used.

### 7. Safeguards

Personal information shall be protected by security safeguards appropriate to the sensitivity of the information.

### 8. Openness

An organization shall make readily available to individuals specific information about its policies and practices relating to the management of personal information.

### 9. Individual Access

Upon request, an individual shall be informed of the existence, use, and disclosure of his or her personal information and shall be given access to that information. An individual shall be able to challenge the accuracy and completeness of the information and have it amended as appropriate.

### 10. Challenging Compliance

An individual shall be able to address a challenge concerning compliance with the above principles to the designated individual or individuals accountable for the organization's compliance.

<p><b>For more information on the HBOC Society Privacy Policy contact:</b></p>	<p><b>For copies of the <i>CSA Model Code for the Protection of Personal</i></b></p>
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## The Privacy Policy in Detail

### 1. Scope

This policy applies to all personal information collected, used, or disclosed by the HBOC Society, whether in oral, electronic, or written form.

### 2. Definitions

The following definitions apply in this Privacy Policy:

**Collection** - the act of gathering, acquiring, or obtaining personal information from any source, including third parties, by any means.

**Consent** - voluntary agreement with what is being done or proposed. Consent can be either express or implied. Express consent is given explicitly, either orally or in writing. Express consent is unequivocal and does not require any inference on the part of the HBOC Society. Implied consent arises where consent may reasonably be inferred from the action or inaction of the individual.

**Disclosure** - making personal information available to others outside the HBOC Society.

**Personal information** - information about an identifiable individual that is recorded in any form. Personal information does not include the name, title, business address or telephone number of any staff member of the HBOC Society.

**Use** - refers to the treatment and handling of personal information within the HBOC Society.

### 3. Commentary

#### 3.1

The ten principles of this Privacy Policy are interrelated and should be read as a whole. Where there is a note following a principle (see principles 3 and 9), it forms an integral part of the principle.

#### 3.2

Each of the principles is followed by a commentary on the principle. The commentaries are intended to indicate the significance and the implications of the principles.

### 4. Principles

#### 4.1 Principle 1 - Accountability

The HBOC Society is responsible for personal information under its control and shall designate one or more individuals who are accountable for the HBOC Society's compliance with the following principles.

##### 4.1.1

Accountability for the HBOC Society's compliance with the principles rests with the Board of Directors of the HBOC Society, even though other individuals within the HBOC Society may be responsible for the day-to-day collection and processing of personal information.

**4.1.2**

The HBOC Society is responsible for personal information in its possession or custody, including information that has been transferred to a third party for processing. The HBOC Society shall use appropriate means to provide a comparable level of protection while the information is being processed by a third party.

**4.1.3**

The HBOC Society shall implement policies and practices to give effect to the principles, including

- (a) implementing procedures to protect personal information;
- (b) establishing procedures to receive and respond to complaints and inquiries;
- (c) training staff and communicating to staff information about the HBOC Society 's policies and practices; and
- (d) developing information to explain the HBOC Society 's policies and procedures.

**4.2 Principle 2 - Identifying Purposes**

*The purposes for which personal information is collected shall be identified by the HBOC Society at or before the time the information is collected.*

**4.2.1**

The HBOC Society will document the purposes for which personal information is collected in order to comply with the Openness principle (Clause 4.8) and the Individual Access principle (Clause 4.9).

**4.2.2**

The HBOC Society collects personal information for the following purposes:

- a) to facilitate communication with and between members;
- b) to match individuals desirous of support or information with those with the related expertise or information; and
- c) to determine the demographics of members in order to apply for funding, set agendas, and network with similar organizations.

**4.2.3**

The identified purpose(s) will be specified at or before the time of collection to the individual from whom the personal information is collected. Depending upon the way in which the information is collected, this may be done orally or in writing.

**4.2.4**

When personal information that has been collected will be used for a purpose not previously identified, the new purpose shall be identified prior to use. Unless the new purpose is required by law, the consent of the individual will be sought before information can be used for that purpose.

### **4.3 Principle 3 - Consent**

*The knowledge and consent of the individual are required for the collection, use, or disclosure of personal information, except where inappropriate.*

**Note:** *In certain circumstances personal information can be collected, used, or disclosed without the knowledge and consent of the individual. For example, legal, medical, or security reasons may make it impossible or impractical to seek consent. When information is being collected for the detection and prevention of fraud or for law enforcement, seeking the consent of the individual might defeat the purpose of collecting the information. Seeking consent may be impossible or inappropriate when the individual is a minor, seriously ill, or mentally incapacitated.*

#### **4.3.1**

Consent is required for the collection of personal information and the subsequent use or disclosure of this information. The HBOC Society will strive to will seek express consent for the use or disclosure of the information at the time of collection. In certain circumstances, consent with respect to use or disclosure may be sought after the information has been collected but before use (for example, when the HBOC Society wants to use information for a purpose not previously identified).

#### **4.3.2**

The HBOC Society will make a reasonable effort to explain the identified purpose(s) in such a manner that the individual can reasonably understand how the information will be used or disclosed.

#### **4.3.3**

Because medical information is almost always considered to be sensitive, the HBOC Society will always seek an individual's express consent to future uses and disclosures, where such information is collected from the individual.

#### **4.3.4**

Implied consent is appropriate when the information is less sensitive. Consent can also be given by an authorized representative (such as a legal guardian or a person having power of attorney).

#### **4.3.5**

An individual may withdraw consent at any time, subject to legal or contractual restrictions and reasonable notice. The HBOC Society shall inform the individual of the implications of such withdrawal.

### **4.4 Principle 4 - Limiting Collection**

*The collection of personal information shall be limited to that which is necessary for the purposes identified by the HBOC Society. Information shall be collected by fair and lawful means.*

#### **4.4.1**

The HBOC Society will collect only the personal information that is necessary to fulfil the purposes identified.

**4.4.2**

The HBOC Society will not collect information by misleading or deceiving individuals about the purpose for which information is being collected.

**4.4.3**

The HBOC Society may also collect personal information from other sources including third parties who represent that they have the right to disclose the information.

**4.5 Principle 5 - Limiting Use, Disclosure, and Retention**

*Personal information shall not be used or disclosed for purposes other than those for which it was collected, except with the consent of the individual or as required by law. Personal information shall be retained only as long as necessary for the fulfillment of those purposes.*

**4.5.1**

The HBOC Society, when using personal information for a new purpose, will document this purpose and will seek the consent of the individual for this new purpose.

**4.5.2**

Only HBOC Society staff members with a need to know, or whose duties reasonably so require, are granted access to personal information.

**4.5.3**

The HBOC Society shall develop guidelines and implement procedures with respect to the retention of personal information. These guidelines should include minimum and maximum retention periods. Personal information that has been used to make a decision about an individual shall be retained long enough to allow the individual access to the information after the decision has been made.

**4.5.4**

Personal information that is no longer required to fulfil the identified purposes should be destroyed, erased, or made anonymous. The HBOC Society shall develop guidelines and implement procedures to govern the destruction of personal information.

**4.6 Principle 6 - Accuracy**

*Personal information shall be as accurate, complete, and up-to-date as is necessary for the purposes for which it is to be used.*

**4.6.1**

The extent to which personal information shall be accurate, complete, and up-to-date will depend upon the use of the information, taking into account the interests of the individual. Information shall be sufficiently accurate, complete, and up-to-date to minimize the possibility that inappropriate information may be used to make a decision about the individual.

**4.6.2**

The HBOC Society shall only update personal information when it is necessary to fulfil an identified purpose or upon request by an individual.

**4.7 Principle 7 - Safeguards**

*Personal information shall be protected by security safeguards appropriate to the sensitivity of the information.*

**4.7.1**

The HBOC Society shall protect personal information against loss or theft, as well as unauthorized access, disclosure, copying, use, or modification. The HBOC Society shall protect personal information regardless of the format in which it is held.

**4.7.2**

The nature of the safeguards will vary depending on the sensitivity of the information that has been collected, the amount, distribution, and format of the information, and the method of storage. More sensitive information shall be safeguarded by a higher level of protection.

**4.7.3**

The HBOC Society shall make its staff members aware of the importance of maintaining the confidentiality of personal information.

**4.7.4**

Care shall be used in the disposal or destruction of personal information, to prevent unauthorized parties from gaining access to the information.

**4.8 Principle 8 - Openness**

*The HBOC Society shall make readily available to individuals specific information about its policies and practices relating to the management of personal information*

**4.8.1**

The HBOC Society shall be open about its policies and practices with respect to the management of personal information. HBOC Society will make this information readily available in a form that is easy to understand.

**4.8.2**

The information made available shall include

- (a) the name/title and contact information of the person who is accountable for the HBOC Society's policies and practices and to whom complaints or inquiries can be forwarded;
- (b) the means of gaining access to personal information held by the HBOC Society; and
- (c) a description of the type of personal information held by the HBOC Society, including a general account of its use.

## 4.9 Principle 9 - Individual Access

*Upon request, an individual shall be informed of the existence, use, and disclosure of his or her personal information and shall be given access to that information. An individual shall be able to challenge the accuracy and completeness of the information and have it amended as appropriate.*

**Note:** *In certain situations, the HBOC Society may not be able to provide access to all the personal information it holds about an individual. The reasons for denying access shall be provided to the individual upon request. Exceptions may include information that is prohibitively costly to provide, information that contains references to other individuals, information that cannot be disclosed for legal, security, or commercial proprietary reasons, and information that is subject to solicitor-client or litigation privilege.*

### 4.9.1

Upon request, the HBOC Society shall inform an individual whether or not the HBOC Society holds personal information about the individual. The HBOC Society shall indicate the source of this information. The HBOC Society shall allow the individual access to this information. However, the HBOC Society may choose to make sensitive medical information available through a medical practitioner. In addition, the HBOC Society shall provide an account of the use that has been made or is being made of this information and an account of the third parties to which it has been disclosed.

### 4.9.2

An individual may be required to provide sufficient information to permit the HBOC Society to provide an account of the existence, use, and disclosure of personal information, and to prove the identity of the individual seeking information. The information provided shall only be used for these purposes.

### 4.9.3

When it is not possible to provide a list of the organizations to which it has actually disclosed information about an individual, the HBOC Society shall provide a list of organizations to which it may have disclosed information about the individual.

### 4.9.4

The HBOC Society shall respond to an individual's request within a reasonable time and at minimal or no cost to the individual. The requested information shall be provided or made available in a form that is easy to understand.

### 4.9.5

When an individual successfully demonstrates the inaccuracy or incompleteness of personal information, the HBOC Society shall amend the information as required. Depending upon the nature of the information challenged, amendment involves the correction, deletion, or addition of information. Where appropriate, the amended information shall be transmitted to third parties having access to the information in question.

### 4.9.6

When a challenge is not resolved to the satisfaction of the individual, the substance of the unresolved

challenge shall be recorded by the HBOC Society. When appropriate, the existence of the unresolved challenge shall be transmitted to third parties having access to the information in question.

#### **4.10 Principle 10 - Challenging Compliance**

*An individual shall be able to address a challenge concerning compliance with the above principles to the designated individual or individuals accountable for the HBOC Society's compliance.*

##### **4.10.1**

The HBOC Society shall put accessible and simple procedures in place to receive and respond to complaints or inquiries about its policies and practices relating to the handling of personal information.

##### **4.10.2**

The HBOC Society shall inform individuals who make inquiries or lodge complaints of the existence of relevant complaint mechanisms.

##### **4.10.3**

The HBOC Society shall investigate all complaints. If a complaint is found to be justified through either the internal or external complaint review process, the HBOC Society shall take appropriate measures, including, if necessary, amending its policies and practices.