

PRIVACY COMMITTEE

Terms of Reference

The Privacy Committee is a committee of the Board of Directors of the Association of Hemophilia Clinic Directors of Canada. Its mandate is to maintain and protect the privacy of the patient population represented by the AHCDC.

DEFINITIONS:

AHCDC – Association of Hemophilia Clinic Directors of Canada: A national organization of physicians responsible for the provision of care to individuals with hereditary bleeding disorders.

Privacy – The right of an individual to control who has access to their personal identifying and health information.

Security – Maintenance and protection of the integrity of the intellectual and physical property of the AHCDC.

HTC – Hemophilia Treatment Center: The clinical setting for provision of care to individuals with hemophilia and other hereditary bleeding disorders by the multidisciplinary team.

CHARMS – Canadian Hemophilia Assessment and Resource Management System: A PC-based software program to store and summarize health-related data required for the management of individuals with hemophilia at individual HTCs.

CHR – Canadian Hemophilia Registry: A registry of Canadians with hereditary bleeding disorders designated to promote educational, administrative, and research initiatives of the AHCDC.

PREAMBLE:

As a national organization, the AHCDC collects and utilizes information from the Canadian HTCs in coordinating the care and treatment of persons with inherited bleeding disorders. Information collected by the AHCDC may also be used in collaborative research endeavours destined to improve the diagnosis and management of inherited bleeding disorders, and to facilitate the provision of therapeutic products to the HTCs and other health care facilities.

Two national registries, CHARMS and CHR, are maintained by the AHCDC specifically for these purposes. The information collected in these registries can include identifying demographics and specific details of the patient's diagnosis, symptoms, and treatments. While this is vital to the purpose of the registries, and the overall mandate of the AHCDC to improve the care of persons with inherited bleeding disorders, the information must be safeguarded to ensure the privacy of the individual patients. In addition to the registries, specific information may be solicited directly from members of the AHCDC and the individual HTC's, often to support novel clinical, therapeutic, and research endeavors. There are also occasional requests for personal information by representatives of the therapeutic products industries.

With the increase in variety and frequency of requests for patient information, the Board of the AHCDC decided that it was important to establish a formal process to review the privacy implications of these requests. Since most privacy legislation falls under the jurisdiction of the individual provinces, this presents an added layer of complexity for the AHCDC as a national organization. The Privacy Committee is therefore created to ensure the privacy and security of the AHCDC registries, and to review the privacy implications of new requests for patient information from members of the AHCDC and its HTC's.

MEMBERSHIP:

The Committee will consist of five individuals, who are all members of the Association of Hemophilia Clinic Directors of Canada. The Chair will be appointed by the Board of Directors, and will also serve as a member of the CHARMS sub-committee. One member will represent the CHR and CHARMS sub-committees. The other three members will be selected from the general membership of the AHCDC, with an effort to ensure that the committee as a whole represents the geographic distribution of the AHCDC as well as the adult and pediatric populations. At least one member of the committee will be from Quebec.

For voting purposes, a simple majority of the members is sufficient for a motion or decision to be accepted. The Chair will cast the deciding vote in the event of a tie.

TERM OF OFFICE:

The Chair and members of the Committee will be appointed for three-year terms, which can be renewed at the discretion of the Executive. At the conclusion of the term of service of the Chair, that individual will be asked to serve one further term as a member of the Committee in order to provide continuity within the Committee.

MEETINGS:

The committee will meet at least semi-annually by teleconference. One meeting will be held in conjunction with the Annual General Meeting of the AHCDC in lieu of a teleconference. In the event of a Privacy or Security issue that requires urgent attention and consideration by the Committee, an *ad hoc* meeting can be called at the discretion of the Chair with 14 days notice.

RESPONSIBILITY AND REPORTING:

The Chair of the Committee will report directly to the Executive of the AHCDC regarding the deliberations and decisions of the Committee. Issues relating to Privacy or Security raised by Members of the AHCDC should be communicated directly to the Chair for review. For simple concerns, the Chair will review the issue and make recommendations, with further Committee review at the next scheduled meeting. Where these concerns are felt to have a more significant impact or require broader review and discussion, the Chair will inform the Executive, and convene a meeting of the Committee as described above.

ROLE:

The Committee will review Privacy and Security concerns relevant to the activities of the AHCDC and its constituent HTC's, including the ongoing activities and administration of CHR and CHARMS. Issues raised will be evaluated with reference to the Canadian Standards Association Model Code for the Protection of Personal Information (www.csa.ca/cm/ca/en/privacy-code/publications), which has been incorporated within the federal PIPEDA legislation. This code embraces ten guiding principles of privacy, which are summarized as follows:

1. Accountability – An organization is responsible for the personal information under its control, and shall designate an individual or individuals who are accountable for the organization's compliance.
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.
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.
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.