

CANADIAN HEMOPHILIA REGISTRY

OPERATING GUIDELINES

1. The Canadian Hemophilia Registry is a registry of individuals with hereditary bleeding disorders owned and operated by the Association of Hemophilia Clinic Directors of Canada.
2. Distribution of data from the registry requires agreement by the clinic directors.
3. Clinic directors approve the form in which data is made publicly available. From 1988 till the present time (May 2003), and until otherwise stated, data which is made available is:
 - a. Collated – no individual data.
 - b. National – no provincial or clinic data.
 - c. **Addendum, approved at AHCDC Annual Meeting, May, 2005**, to facilitate research by members:
 - i. Access to data at the CHR website will remain unchanged, as in 3a. and 3b. and will continue to be accessible to the public.
 - ii. In addition, Members of AHCDC alone may receive, on request:
 1. Collated national summaries with variations on age groups.
 2. Complete or partial database in spreadsheet form with deletion of the variables clinic, province, HIV, and HCV.
 3. All other requests, particularly where individual clinic or provincial data is requested, requires individual clinic approvals and sometimes AHCDC Board approval.
4. Clinic directors are responsible for the accuracy of data in the CHR.
5. Ownership of data is with individual clinics and patients.
6. Ownership of the CHR software is with AHCDC.
7. Data is both anonymous (no names), and confidential (secure, and not linked to other databases). The registry data is kept on a server at Hamilton Health Sciences, McMaster Site, with security precautions as per hospital patient data, with the exception that access software is available only to the director of the registry and the developer (Cecilia Stiles, MDT software).
8. The director of the CHR is responsible for maintaining the database, for data entry, for security, for keeping backup copies of data and for supplying data on request according to agreement by the clinic directors.
9. The CHR director operates a program of publication, with the expectation of at least one abstract or article from the registry per year.

May 11, 2003

May 29, 2005, revised.

I. Walker