

Guidelines for Retention and Maintenance of Clinical Genetics Records

Developed by the Ethics and Public Committee, CCMG

Preamble

Issues related to the retention and maintenance of clinical genetics records* may differ from those of the general health record because of the very nature of genetic information. Results of genetics consultations and test results relate not just to individuals, but to families, and have potential significance for future generations as well. Most genetics departments across Canada have been in existence less than 30 years. As time goes on, constraints of space and resources to maintain records may increasingly influence genetics departments to consider whether records should be destroyed as per provincial regulations for hospital/medical records, stored elsewhere or integrated into the main health record of the institution.

**Clinical genetics records are those found in the charts of patients in a clinical genetics centre/clinic. While they may include laboratory results, this term specifically does not include those patient records that are normally kept in laboratory files.*

The Ethics and Public Policy Committee of the CCMG was therefore asked by the Board to develop guidelines to assist genetic departments in determining policies for clinical genetics records. A review of the relevant medical literature regarding retention and storage of genetics records was conducted. In addition, provincial regulations for maintenance of medical records in several provinces were reviewed. Finally, a survey of 21 genetic centres across Canada was conducted (see Appendix 1.) A policy was developed and reviewed by all members of the committee. The following guidelines were approved by the CCMG membership at its 2002 AGM.

Recommended Guidelines*

1. Clinical genetics records should be maintained indefinitely except in certain circumstances where the information will be of minimal importance to future interaction in genetics with the patient or other members of the family e.g. AMA patients with normal amniocentesis results. In some circumstances, genetics departments may choose to maintain only key parts of the record e.g. consultation, test results. Electronic data storage, microfilm etc. may be required to address ongoing space needs.
2. Clinical genetics records should be maintained as separate charts from the institution's main health record. The genetics department should be responsible for informing the institution's health records department of the existence of a patient record in genetics.

** These guidelines are in addition to local hospital and provincial regulations for hospital/medical records.*