

CANADIAN COMPREHENSIVE CARE STANDARDS FOR HEMOPHILIA AND OTHER INHERITED BLEEDING DISORDERS

First Edition
June 2007

Authored by the Canadian Hemophilia Standards Group¹



CSWHC

¹ A committee of the Association of Hemophilia Clinic Directors of Canada in collaboration with the Canadian Hemophilia Society (CHS), the Canadian Association of Nurses in Hemophilia Care (CANHC), Canadian Physiotherapists in Hemophilia Care (CPHC), and Canadian Social Workers in Hemophilia Care (CSWHC).

FOREWARD

This document was completed by a national multidisciplinary committee, including members of the CHS (Canadian Hemophilia Society), to further the initiatives of the AHCDC (Association of Hemophilia Clinic Directors of Canada) in standardizing the care of people with bleeding disorders nationally, as recommended by the 1998 Standards of Care Conference¹. The authors acknowledge a long standing wish for national standards dating from the conference Comprehensive Care for the Canadian Hemophiliac, Winnipeg, May 1978²

The document is intended for use by Hemophilia Treatment Centres, hospital administrations, and provincial Ministries of Health.

The Vision is to provide comprehensive care to all individuals with inherited bleeding disorders, guided by clear standards, facilitated by engagement with stakeholders, and driven by needs and best practice, resulting in best outcomes.

The focus of these standards is on the structural and resource requirements necessary for a Hemophilia Treatment Centre to effectively provide care, and on its functions and responsibilities. These standards are not intended to guide therapies, these being most properly addressed by clinical practice guidelines.

COMMITTEE MEMBERS³

Dr. Dorothy Barnard
Morna Brown
Maureen Brownlow
David Page
Erica Purves
Julia Sek
Mary Jane Steele
Dr. Jerry Teitel (co-chair)
Dr. Irwin Walker (co-chair)
Dr. Molly Warner
Pam Wilton

¹ Winnipeg II Conference, Winnipeg, April 1998. Report available at www.ahcdc.ca

² Proceedings available from the Canadian Hemophilia Society

³ See Appendix for details on individual members



CONTENTS

FOREWARD	2
COMMITTEE MEMBERS.....	2
PREAMBLE	5
Guiding Principles.....	5
Premises	5
Purpose.....	6
Characteristics of effective programs	6
STANDARDS	7
Principles.....	7
The Population	7
Core team	8
Extended team members	8
Diagnostic and Therapeutic Principles.....	8
Services	9
Responsibilities of an HTC	9
STANDARDS – 1. SCOPE OF CARE.....	10
Key Indicators - 1. Scope of Care	11
STANDARDS – 2. QUALITY MEASURES	13
Key Indicators - 2. Quality Measures.....	15
STANDARDS - 3. THERAPEUTIC SERVICES.....	16
Key Indicators - 3. Therapeutic Services	18
APPENDICES	20
Bibliography.....	21
Glossary.....	23
Target population, diagnoses and services	26
Scope of practice statements	27
Resources	28
Members, Canadian Hemophilia Standards Group	30
Additional Comments	31
Acknowledgments.....	32

Hemophilia Care

“Medical care for hemophilia is specialized. A person with hemophilia must receive care from healthcare workers who have expert knowledge of the bleeding disorder. The wide-ranging needs of people with hemophilia and their families are best met through Hemophilia Treatment Centres rather than by individual doctors.” - World Federation of Hemophilia: *Organizing a National Programme for Comprehensive Hemophilia Care.*



PREAMBLE

Guiding Principles

- : Achieving best treatment outcomes
- : Treating all people equitably
- : Respecting individuals' autonomy and privacy
- : Creating an atmosphere of honesty, integrity & trust

Premises

- : Improved quality of life is the ultimate goal of care, with an emphasis on measurable outcomes and independent living.
- : Inherited bleeding disorders are rare and therefore collaboration among Hemophilia Treatment Centres (HTCs) and networks needs to be encouraged.
- : Bleeding disorders and their treatments are associated with a number of complications—medical, psychological and social—that may affect quality of life of affected individuals and so care needs to be comprehensive.
- : Evaluation and documentation of clinical outcomes are essential components of a comprehensive program.
- : Standards of care are measures that Hemophilia Treatment Centres can adhere to and which can be used for auditing. Key indicators are signals that demonstrate whether a standard has been attained. They provide a way in which to measure and communicate the impact or result of the standard, as well as the process.
- : Accountability for utilization of factor replacement product is necessary due to its potential to cause adverse events and its high cost; this is equally true for products used in centres and at home in supervised home therapy programs.
- : HTCs have a responsibility to participate in research, education and innovation to the degree that they are capable. : Regional differences within the province or region must be acknowledged in the provision of care for people with bleeding disorders.

Purpose

The purpose of national standards is to encourage Hemophilia Treatment Centres to adhere to uniform practices that are desirable, accountable, transparent and organized.

Comprehensive care is the recommended method of care delivery, enabling people with inherited bleeding disorders to have access to effective and expert health care. The provision of high quality multidisciplinary care will improve patient outcomes and optimize resource utilization.

Standards will help in:

- Achieving recognition of Hemophilia Treatment Centres by hospital and provincial authorities, thereby enabling the provision of optimal care according to recognized standards
- Assuring equitable access and quality evidence-based care across Canada
- Establishing a reference for future advances and needs
- Establishing a focus and unifying force for staff of various disciplines that are serving the small and geographically dispersed population of people with inherited bleeding disorders
- Promoting discussion and research regarding optimal ways to deliver care
- Providing the basis for design of clinics, for accreditation, and for audit and evaluation.

Characteristics of effective programs

Effective programs....

- : deliver comprehensive care through an integrated, multidisciplinary team.
- : partner with patients to foster and facilitate self-management and independence.
- : have the capacity to tailor management to the individual's needs and abilities.
- : adhere to guidelines and standards.
- : regularly participate in quality assurance.
- : consult with other programs.
- : participate in collaborative research.

STANDARDS

Principles

1. Striving to enrol all individuals with bleeding disorders in the Hemophilia Treatment Centre (HTC) region
2. Making accurate diagnosis.
3. Performing genetic diagnosis and counselling
4. Managing all aspects of bleeding episodes
5. Prevention
6. Diagnosis
7. Treatment
8. Rehabilitation
9. Advocating both for individuals and the patient group
10. Facilitating and maintaining linkages and consultations with other health care practitioners and services
11. Coordinating care for the individual, both within the institution and beyond
12. Preventing and treating complications and enabling rehabilitation
13. Promoting self-fulfillment, self-determination and societal integration
14. Monitoring patients' use of factor concentrate

The Population served includes people with:

- 1) Hemophilia A & B, both inherited and acquired
- 2) Von Willebrand disease, both inherited and acquired
- 3) Rare inherited bleeding disorders
- 4) Heterozygosity for (carriers of) hemophilia A and B

Core team

Permanent team members with specific expertise and experience in the management of bleeding disorders are required. The following members are essential and should be readily accessible to one another.

- : Medical Director (adult or pediatric hematologist or internist)
- : Nurse Coordinator
- : Physiotherapist
- : Social Worker
- : Administrative Assistant

Extended team members

These members are important to the successful delivery of quality health care and must be available within each program or on a referral basis, even if only through agreements with other health care institutions.

- : Orthopedic surgeon
- : Rheumatologist and/or physiatrist
- : Hepatologist
- : Infectious disease/HIV specialist
- : Gynecologist/Obstetrician
- : Geneticist/Genetic Counsellor
- : Dentist
- : Medical experts in pain management
- : Psychiatrist/ Psychologist
- : Childlife specialist (for HTC's that see children)
- : Occupational Therapist

Diagnostic and Therapeutic Principles

1. Care is patient and family centred.
2. Patients and families are partners with the HTC in care decisions.
3. There is universal access of the target populations to the HTC.
4. There is access to prophylactic infusion therapy as appropriate.
5. There is access to home therapy as appropriate.
6. There is choice of treatment product when available.
7. There is choice of HTC and physician when available.
8. Individualized treatment recommendations are developed for all patients.



Services

1. Special hemostasis laboratory
2. Other diagnostic laboratory services
3. Transfusion medicine
4. Diagnostic imaging
5. 24-hour emergency care
6. Home infusion program with appropriate education
7. Access to medical and allied health expertise necessary to satisfy the complex and diverse needs of their patients
8. Factor concentrate utilization management
9. Educational services to other health care services and outside agencies
10. Outreach services

Responsibilities of an HTC

1. Deliver evidenced-based patient care
2. Promoting bleeding disorder care through consultation with other agencies and organizations, in particular CHS, Provincial Governments, CBS, Héma-Québec, Health Canada and Public Health
3. Monitoring product utilization
4. Managing product recalls and notifications
5. Maintenance of patient records
6. Education
 - a. Patients
 - b. Families
 - c. Carriers
 - d. Other health care workers
 - e. Community agencies, such as schools, government agencies
 - f. Emergency rooms throughout the region of the HTC
7. Research
8. Advocacy
9. Surveillance for complications, including inhibitors, adverse drug and transfusion reactions
10. Participation in evaluation and accreditation activities
11. Participation in national databases

STANDARDS – 1. SCOPE OF CARE¹

The HTC will:

1. Establish correct diagnoses.
2. Establish and maintain a full complement of core team members
3. Develop visibility in the bleeding disorder and medical community.
4. Strive to enrol all members of the target population in its region.
5. Establish a collaborative relationship among core team members
6. Establish a routine for patient access to regular and emergency care.
7. Establish a process for referring patients to services not provided within the program.
8. Register patients in CHARMS (Canadian Hemophilia Assessment and Resource Management System) and CHR (Canadian Hemophilia Registry) databases.
9. Provide the patient with documentation that identifies his/her bleeding disorder and recommended treatment.
10. Provide education to affected individuals, family members, health care givers and others as necessary.
11. Have a home infusion program, in which patients and families are instructed in home therapy, including prevention and recognition of bleeds and correct practices.*This is further detailed in "3.11".
12. Provide primary and secondary prophylaxis regimens as appropriate (all pediatric patients with severe hemophilia should be considered).
13. Provide early intervention and follow-up care to reduce long-term complications.
14. Network with outside agencies creating formal linkages to provide efficient access to their services.
15. Encourage & facilitate eligible members to participate in activities of AHCDC, CANHC, CPHC, CSWHC and other relevant HTC working groups.

¹ This section describes which bleeding disorders are to be addressed by the HTC, the required staff, and the administrative structure and responsibilities.

Key Indicators - 1. Scope of Care¹

- 1-1 Patients' factor levels are documented in their clinic records.
- 1-2 The HTC has a complete complement of core team members as listed in the standards.
- 1-3a The HTC has regular communications with the local chapter or region of the Canadian Hemophilia Society.
- 1-3b The HTC has a process in which to communicate to outside agencies about current events / workshops and conferences.
- 1-3c Outside agencies are able to contact team members for information.
- 1-4 The HTC is aware of the pattern of factor concentrate utilization in the region
- 1-5a There is evidence of collaboration among all members.
- 1-5b Core team members contribute to the development of policies, procedures and standards.
- 1-6a Registered patients can access care and follow-up care for acute bleeds.
- 1-6b Non life-threatening bleeds in non inhibitor patients are managed in the ambulatory care setting, so that there is a low hospitalization rate for bleeding episodes.
- 1-6c Policies & procedures are available for the treatment of non-urgent, urgent and emergency bleeding episodes.
- 1-7a The HTC has a referral list for secondary team members and utilizes their services routinely.
- 1-7b Secondary team members are extended invitations to team educational workshops and activities.
- 1-7c The core team is aware of referral procedures to secondary team members.
- 1-8a CHARMS software is available in the HTC.
- 1-8b All core team members have access to the CHARMS program.
- 1-8c Clerical work for data entry is kept current.
- 1-9 Wallet cards or *FactorFirst* cards are issued to registered patients and updated as needed.
- 1-10 Policies and procedures for education of newly diagnosed patients are available.
- 1-10 A variety of educational resources are available to distribute to patients, families and community.
- 1-11a Policies & procedures are available on how to administer the home therapy program.
- 1-11b There are patients registered in the home therapy program and the list of participants is available.
- 1-11c There is documentation in the patient health record about participation in home therapy program (including date of certification)
- 1-12a Prophylaxis therapy is made available to the appropriate patients.
- 1-12b A current list of patients on prophylaxis is available.

¹ Numbering of Key Indicators refers to the corresponding Standards

-
- 1-13a The HTC has access to a special hemostasis laboratory, transfusion medicine department, and diagnostic imaging department.
 - 1-13b The HTC has a procedure for assigning priority for new patient referrals.
 - 1-14 Contact information for the HTC is current in listings with the Canadian Hemophilia Society, the World Federation of Hemophilia and parent hospital.
 - 1-15a Core team members are members of relevant organizations and / or working groups within the bleeding disorder community and communicate regularly with these organizations.
 - 1-15b Core team members, when able, serve on appropriate committees within the organization (AHCDC, CANHC, CPHC, and hospital).

STANDARDS – 2. QUALITY MEASURES^{1,2}

The HTC will:

1. Maintain health records according to legislation, which must include:
 - i. History and physical examination
 - ii. Diagnosis and treatment recommendations
 - iii. Operative/special procedure notes and records
 - iv. Interdisciplinary progress notes
 - v. Medication records
 - vi. Consent forms
 - vii. Adverse events/allergies
 - viii. Records of home therapy program (teaching, home visit to initiate program, and annual certification)
 - ix. Records of telephone communications
2. Participate in data collection and submission to CHARMS including:
 - i. Patient demographics
 - ii. Factor utilization
3. Submit anonymous data to the *Centre Point* module of CHARMS and to the CHR, as required by AHCDC. AHCDC will pool and collate factor concentrate utilization data and make it available to the operators of the blood system to plan purchases, flag inconsistencies, outliers and adverse events and to conduct efficient recalls and advisories as necessary. AHCDC will also use data for research planning, and various administrative and political purposes.
4. Adhere to provincial health information privacy protection acts.
5. Be supported by its host hospital and the provincial Ministry of Health.
6. Accept accountability for the appropriate use of all factor concentrates distributed within its catchment area to registered patients with inherited bleeding disorders. This excludes cryoprecipitate and fresh frozen plasma, but includes all plasma-derived and recombinant concentrated clotting factors distributed by Canadian Blood Services and Héma-Québec.
7. Participate in a formal accreditation and evaluation process once it is established.

¹ This section describes expected activities of an HTC that contribute to the quality of both the individual centre and the Canadian HTC network.

² “A degree of excellence” – Merriam-Webster

“Conformance of a product or process with pre-established specifications or standards” – Federation for the Accreditation of Cellular Therapy.

-
8. Mentor, where possible, students and trainees in the health professions.
 9. Establish mechanisms to acknowledge and review compliments, complaints and special requests. These compliments and complaints are documented and reviewed periodically.

Key Indicators - 2. Quality Measures¹

- 2-1a Hospital records contain current HTC documentation that may include assessments by core team members stating patient goals, team recommendations, patient issues, and patient progress.
- 2-1b Hospital records and clinic charts include documentation of telephone calls for patient advice and follow-up.
- 2-2a Data is routinely exported from CHARMS to Centre Point.
- 2-2b Factor utilization reports are available from the local CHARMS program.
- 2-2c The HTC has the ability to monitor expiry dates of factor concentrates within its jurisdiction via the CHARMS program.
- 2-3a Data is routinely exported from CHARMS to Centre Point.
- 2-3b Registered patients are assigned a CHR number.
- 2-4 If the HTC has clinic charts, the charts are stored appropriately to maintain privacy and confidentiality, and are accessible to appropriate team members.
- 2-5a The HTC participates in hospital or peer evaluation and responds to critical appraisal.
- 2-5b There is a process to request adjustment in resources and to monitor services available to the patient population.
- 2-6 Data is routinely exported from CHARMS to Centre Point.
- 2-7 Centre volunteers to undergo accreditation process or responds to requests to do so.
- 2-8 HTCs located in academic healthcare institutions provide professional educational opportunities.
- 2-9 Patients and families have a mechanism in which to communicate concerns and compliments.


¹ Numbering of Key Indicators refers to the corresponding Standards

STANDARDS - 3. THERAPEUTIC SERVICES¹

The HTC will:

1. Provide the appropriate professional care for their patients, recognizing the need for pediatric and adult medical expertise as appropriate.
2. Provide a comprehensive evaluation (including laboratory testing) at least annually for adult patients and semi-annually for children. This frequency is recommended for those with higher bleeding risk; for those with a lower bleeding risk a less frequent schedule will be appropriate. The evaluation will include updating wallet cards (treatment recommendations).
3. Provide assessments from each core team member at least annually. Patients will have additional access to core team members as required.
4. Provide emergency departments and family physicians with diagnosis and treatment recommendations for registered patients, consistent with the PHIPA and the hospital's health records policy. The HTC will arrange for qualified 24-hour medical coverage and consultative services for the target population.
5. Educate patients and families on the best way to advocate for and to access emergency care and other services.
6. Utilize, as appropriate, clinical practice guidelines published by AHCDC and other expert bodies for the management of bleeding episodes, inhibitors and special or surgical procedures.
7. Establish formal links to provide access to special hemostasis testing, genetic testing, and treatment for hemophilia and its complications.
8. Work in collaboration with patients and their families to promote health and to enhance ability to cope with a chronic health condition.
9. Provide education and recommendations to other community professionals who provide services to patients with inherited bleeding disorders.
10. Provide prophylaxis (primary and secondary) to patients in accordance with AHCDC recommendations and best practice.

¹ This section describes the actions required of an HTC in the direct delivery of therapeutic services.

- 
11. Provide a home therapy program to all appropriate patients and monitor its effectiveness for each individual. The home therapy program will include comprehensive training in intravenous technique and procedures for both care givers and patients themselves, as appropriate, safe and responsible handling and storage of factor concentrates and safe disposal of used equipment and supplies. Maintenance of home therapy records will be encouraged and routinely reviewed, to help in making treatment recommendations.
 12. Provide injection equipment and other supplies to patients.
 13. Provide management for patients with inhibitors with reference to guidelines issued by the AHDCDC and other expert bodies.
 14. Be located in a facility that should be readily accessible to people with disabilities.
 15. Be located within an Ambulatory Clinic area to facilitate prompt assessment and treatment of acute bleeding episodes.
 16. Be located in a facility that has or is linked with an Emergency Department where patients can obtain treatment outside of regular hours.

Key Indicators - 3. Therapeutic Services¹

- 3-1 The members of the HTC have the appropriate training and qualifications to provide care to the patient population.
- 3-2a The number of assessment clinics offered is sufficient to meet the standard of annual and semi-annual patient evaluation.
- 3-2b The HTC provides a mechanism for team members to share knowledge with each other to promote best patient outcomes.
- 3-3 Core team members are available for assessment clinics and urgent care.
- 3-4a The HTC has resources available to ER departments regarding treatment and complications.
- 3-4b HTC provides treatment recommendations to emergency departments and family physicians.
- 3-5a Educational information is offered to patients and family on current issues / events related to bleeding disorders.
- 3-5b Each core team member provides education and support to patients and families.
- 3-5c Team members ensure that patients have sufficient information to make informed decisions.
- 3-6 There are reference materials available to team members and students (i.e. AHCDC Clinical Practice Guidelines, journal articles and texts).
- 3-7 There are formal links to specialized laboratories and Canadian Blood Services
- 3-8a When participating in research or clinical trials, team members ensure the safety and well-being of the patient above all other objectives.
- 3-8b The HTC has contact information available (e.g. business cards).
- 3-9a When a patient moves to a location served by another HTC, the two centres will ensure that a formal transfer takes place promptly, including the forwarding of all relevant medical records, with patient consent.
- 3-9b Educational information is offered within the community as requested or needed (i.e. school, daycare).
- 3-10 There are reference materials available to team members and students (i.e. AHCDC Clinical Practice Guidelines, journal articles and texts).
- 3-11 The team has a mechanism to evaluate the home therapy program outcomes with participants.
- 3-12 Patients receive injection equipment and supplies free of charge
- 3-13 There are reference materials available to team members and students (i.e. AHCDC Clinical Practice Guidelines, journal articles and texts).
- 3-14 Physical clinic space is appropriate for people with disabilities or mobility aids.
- 3-15a There is private clinic space available for acute assessments and treatment.

¹ Numbering of Key Indicators refers to the corresponding Standards

-
- 3-15b The HTC ensures an adequate stock of factor concentrates is maintained within its institution.
 - 3-16 The Emergency Department affiliated with the HTC has recommended treatment guidelines for registered patients.



APPENDICES

Bibliography

- World Federation of Hemophilia, *Guidelines for the Management of Hemophilia*, 2005
- National Hemophilia Foundation, *Comprehensive Care for People with Hemophilia*, 1991
- Haemophilia Alliance (UK). *A National Service Specification for Haemophilia and Other Inherited Bleeding Disorders*. 2001.
<www.haemophiliaalliance.org.uk>.
- Szucs TD et al. *Resource Utilization in Hemophiliacs Treated in Europe: Results from the European Study on Socioeconomic Aspects of Hemophilia Care*. *Haemophilia* (1998), 4, 498-501
- Soucie JM, B.L. Evatt and the Hemophilia Surveillance System, Hematologic Diseases Branch, Centers for Disease Control and Prevention. *Care in Hemophilia Treatment Centers (HTC) is Associated with Lower Mortality Risk among Persons with Hemophilia in the United States*, *Haemophilia*, Volume 4, Number 3, May 1998
- Soucie JM, J. Symons IV, B. Evatt, D. Brettler, H. Huszti, J. Linden & The Hemophilia Surveillance System Project investigators. *Home-based factor infusion therapy and hospitalization for bleeding complications among males with haemophilia*, *Haemophilia*, Volume 7 Issue 2, March 2001
- Soucie JM, Nuss R, Evatt B et. al. *Mortality among males with hemophilia: relations with source of medical care*. *The Hemophilia Surveillance System Project Investigators*. *Blood* July 2000; 96:437-442.
- Canadian Council on Health Services Accreditation (CCHSA) 1995
- Wong J, Gilbert J & Kilburn L *Seeking Program Sustainability in Chronic Disease Management: The Ontario Experience*, May 2004
- The Disease Management Approach in Ontario: Current Perspectives, Feb 2002
- Report On A Conference: Standards for Hemophilia Care in Canada. Winnipeg, Manitoba, 1998
- The Association of Hemophilia Clinic Directors of Canada. *Clinical Practice Guidelines*. 1999
- The Ontario Hemophilia Program Directors Group (OHPDG). *Optimal Comprehensive Care for Persons with Hemophilia and Related Disorders Resident in the province of Ontario*. November 1995

Kasper CK. Inherited Plasma Clotting Factor Disorders and their Management. Revised Edition. July 2000

Glossary

ACCEPTABILITY: The extent to which each service provided meets the expectations of the patient, family, providers and accreditor.

ACCESSIBILITY: Ability of client to obtain care and treatment or service at the right place and at the right time, based on their respective needs.

AHDC: The Association of Hemophilia Clinic Directors of Canada.

CANHC: Canadian Association of Nurses in Hemophilia Care.

CPHC: Canadian Physiotherapists in Hemophilia Care.

CSWHC: Canadian Social Workers in Hemophilia Care.

CCHSA: The Canadian Council on Health Services Accreditation.

CHARMS: Canadian Hemophilia Assessment and Resource Management System.

CHR: Canadian Hemophilia Registry.

CHS: Canadian Hemophilia Society.

CPHC: Canadian Physiotherapists in Hemophilia Care.


CLIENT: Any individual, family, group and/or community (internal or external to the organization) receiving care and treatment, or service from the organization. (See also **PATIENT**.)

CLINICAL PRACTICE GUIDELINES: Systematically developed statements, evidence-based, to help physician and patient make decisions about appropriate health care.

COMPREHENSIVE EVALUATION: Clinical evaluation of a patient's entire health status, with emphasis on issues relating to hemophilia.

EVIDENCE-BASED CARE: Care practice based on evidence of effectiveness, either from previous applications of a therapy in an individual patient, or from research literature.

FAMILY: People with a close relationship to the patient, usually but not always familial. These people may assume an advocacy role for the patient when necessary.



HEALTH: The state of complete physical, mental, and social well-being and not merely absence of illness. Health has many dimensions and is largely culturally defined.

HEALTH CARE TEAM: A multidisciplinary group of professionals who plan, coordinate and oversee health care.

HEALTH PROMOTION: The process of enabling people to increase control over, and to improve their own health.

HEMOPHILIA: In this document the use of 'hemophilia' may be used to refer to the patient group that includes all inherited bleeding disorders.

HOME THERAPY: Intravenous infusion of coagulation factor concentrate, or injection of desmopressin, by an affected person, or other person (usually a family member), in the home or other non-health care setting

HOME THERAPY PROGRAM: An infrastructure involving members of the hemophilia treatment centre and blood supplier, in cooperation with affected individuals and family members, which organizes training, monitoring and outcomes measurements necessary for home therapy.

HTC: Hemophilia Treatment Centre. This refers to the title of the centre and is inclusive of the programs it offers.

INDICATOR: A specific process or outcome that can be categorized or quantified and which reflects quality of care.

INTERDISCIPLINARY: Involving two or more academic, scientific or artistic disciplines.


KEY INDICATORS: Indicators are signals that demonstrate whether a standard has been attained. They provide a way in which to measure and communicate the impact or result of the standard, as well as the process.

MULTIDISCIPLINARY: See interdisciplinary.

OUTREACH: The extension of services to the community. Modes of communication include mail, email, telephone and optimally, in-person.

PATIENT: An individual receiving health care.

PEER REVIEW: Review by individuals from the same discipline and with essentially equal qualifications.



PERFORMANCE INDICATOR: Methods or instruments to estimate or monitor the extent to which the actions of an individual practitioner or whole program conform to practice standards of quality or allow for comparisons between services.

QUALITY: Conformance of a product or process with pre-established specifications or standards.

STANDARD: Desired and achievable level of performance against which actual performance can be compared (CCHSA). Something set up as a rule for measuring or as a model to be followed. (Merriam-Webster)

STANDARDS OF CARE: Statements on quality or quantity of care compared with that which is desired or formally prescribed. They describe the minimum, competent level of care and treatment that can be expected by every patient and identify the expected results (outcomes) of care and treatment.

WORK LOAD MEASUREMENT: Manual or computerized tool for assessing and monitoring the volume of activity provided by a specific team in relation to the needs for the care and treatment, or service they are providing.

Resources for Glossary:

The Canadian Council on Health Services Accreditation (CCHSA), 1995
Canadian Hospital Association, 1994
Canadian Medical Association, 1994
World Health Organization, 1986 & 2000
The Merriam-Webster Dictionary, 2004

Target population, diagnoses and services

DIAGNOSES

- 1) HEMOPHILIA A (deficiency of factor VIII - classical hemophilia)
HEMOPHILIA B (deficiency of factor IX - Christmas disease)
 - X-linked disorder
 - Categories include:
 - Severe < 1% clotting factor protein activity
 - Moderate 1-5% clotting factor protein activity
 - Mild >5-50% clotting factor protein activity
- 2) VON WILLEBRAND DISEASE (VWD)
 - Deficiency in quality or quantity of von Willebrand factor
 - 3 main subtypes:
 - type 1 - partial quantitative deficiency
 - type 2 - qualitative defects
 - type 3 - virtually complete quantitative deficiency
- 3) RARE INHERITED BLEEDING DISORDERS
 - Include deficiencies in factor proteins I, II, V, VII, X, XI, XIII
- 4) INHERITED PLATELET DISORDERS
 - Include disorders characterized by thrombocytopenia and / or abnormal function of platelets
- 5) HEMOPHILIA HETEROZYGOTES (CARRIERS)
 - Heterozygous carriers of the x-linked gene that causes hemophilia A or B
 - Carriers who have a bleeding tendency, fall under category 1
- 6) ACQUIRED HEMOPHILIA & VWD
 - This is due to the development of an inhibitor against factor VIII or VW factor.

SERVICES

- Diagnostic
- Education
- Medical assessment
- Nursing evaluation
- Physical therapy / Musculo-skeletal evaluation
- Psychosocial evaluation
- Genetic assessment / counselling
- Home therapy program
- Outreach
- Research participation (as available and applicable)
- Referral to consultation services (as listed in "secondary services")
- Preoperative assessment
- Management of bleeding

Scope of practice statements

These statements apply to non-physician health care professionals. Scope of practice/service refers to core accountabilities. Scope clarity work is about communicating the contributions of each service provider. For the professional healthcare provider, this refers to those services he/she is accountable for providing based on education and license.

Nurse:

- Provide services that enhance health by assessing, monitoring, detecting and preventing complications associated with certain health situations or treatment plans.
- Provide services that enhance health by assessing, monitoring, detecting and treating the human responses.
- Provide services directed towards prevention of disease and injury and/or the promotion, maintenance or restoration of health.
- Teach skills necessary for the administration and teaching of infusion therapies.

Physical Therapist:

- Identify and assess physical impairments, functional limitations, pain and disability, and their impact on physical ability and function.
- Develop individualized plan of care focused on mutually-determined physical and functional goals.
- Treat and educate to prevent and alleviate physical impairments and to optimize physical function or comfort.

Social Worker:

- Conduct psycho-social assessments and integrate physical and environmental factors.
- Identify and coordinate continuum of care needs.
- Develop therapeutic relationships with patients and families.
- Integrate patient and family perspectives, strengths and self-determination into a collaborative plan of care.
- Counsel and educate.
- Facilitate access to and advocate for resources needed by individuals and group.

Adapted from Clinical Practice Model (CPM) Resource Centre 2005.

Resources

Texts

- Textbook of Hemophilia. 2005. Edited by Christine a. Lee, Erik E, Berntorp and W. Keith Hoots. Blackwell Publishing.
- Congenital Bleeding Disorders: Principles & Practices. 2000 Hemophilia Nursing Alliance (Aventis)
- Living with Haemophilia. 2002, Peter Jones, M.D. 5th Edition, Oxford University Press.
- Musculoskeletal Aspects of Haemophilia. 2000 Edited by E.C. Rodriguez-Merchan, N.J. Goddard and C.A. Lee. Blackwell Publishing.
- Mechanisms in Hematology. 2002. Lyonel G. Isreals and Esther D. Isreals. Core Health Services Inc.

Manuals

- Canadian Hemophilia Society Vision of Comprehensive Care for Persons with Inherited Bleeding Disorders. 1995 CHS
- The Association of Hemophilia Directors of Canada Clinical Practice Guidelines. 1999 AHCDC
- Nursing Guidelines for the Treatment of Hemophilia and Other Inherited Bleeding Disorders. 1995 CANHC
- Report on a Conference: Standards For Comprehensive Care Of Hemophilia In Canada. 1998 CHS
- Inherited Plasma Clotting Factor Disorders and their Management. 2000 WFH
- Guidelines for the Management of Hemophilia. 2005 WFH
- Go For It. 1998 WFH
- The Bleed Stops Here. 1996 Hemophilia Nurses in Ontario, Ottawa General Hospital CANHC
- Nurses' Guide to Bleeding Disorders. 2004 NHF

Canadian Standards

- Canadian Hemophilia Nursing Standards of Practice. 1993
- Standards of Practice for Social Workers in Hemophilia. 1996
- Standards of Physiotherapy Care for People Living With Bleeding Disorders. 1999
- Ontario Hemophilia Comprehensive Care Standards. 2005

Websites

- www.hemophilia.ca Canadian Hemophilia Society
- www.wfh.org World Federation of Hemophilia
- www.hemophilia.org National Hemophilia Foundation (USA)
-
- www.ahcdc.ca Association of Hemophilia Clinic Directors of Canada
- www.bloodservices.ca Canadian Blood Services
- www.hema-quebec.qc.ca Héma-Québec
- www.hemophiliaemergencycare.com Hemophilia Emergency Care

Manufacturers of Factor Replacement Products for the Canadian Market

- Baxter Biosciences:
www.hemophiliagalaxy.com/patients/index.html
- Bayer Biologicals: <http://livingwithhaemophilia.com/>
- Novo Nordisk:
www.novonordisk.com/therapy_areas/haemostasis
- Wyeth: www.hemophiliavillage.com/
- CSL Behring: www.cslbehring.com
- Octapharma www.octapharma.com/corporate/

Journals

- WFH: "Haemophilia World"
- CHS: "Hemophilia Today" (including local Chapter newsletters)
- NHF: "Hemaware"
- Blackwell Publishing: Haemophilia

This list is NOT all inclusive; there are many excellent resources available.

Members, Canadian Hemophilia Standards Group

Dorothy R. Barnard, MD, FRCPC
Section Head, Immunohematology
Dalhousie University
IWK Health Centre
Halifax, Nova Scotia

Morna Brown, RN
Clinical Resource Nurse,
Hemophilia Treatment Centre
Alberta Childrens Hospital
Calgary, Alberta

Maureen Brownlow, MSW, RSW
Social Worker, Hemophilia
Treatment Centre
IWK Health Centre,
Halifax, Nova Scotia

David Page
Director of Programs and Public
Affairs
Canadian Hemophilia Society
Montreal, Quebec

Erica Purves, RN MN NP
(pediatric)
Nurse Practitioner, Hemophilia
Treatment Centre
BC Children's Hospital
Vancouver, British Columbia

Julia Sek, RN, BScN, CCW
Ontario Hemophilia Provincial
Coordinator
St Michael's Hospital
Toronto, Ontario

Mary Jane Steele, PT, BSc,
Physiotherapist, Hemophilia
Treatment Centre
London Health Sciences Centre,
London, Ontario

Jerry Teitel, MD, FRCPC
Director, Hemophilia Treatment
Centre
St Michaels Hospital
University of Toronto

Irwin Walker, MBBS, FRACP,
FRCPC
Director, Hemophilia Treatment
Centre.
Hamilton Health Sciences
Hamilton, Ontario

Molly Warner, MD, FRCPC
Director, Hemophilia Treatment
Centre
Royal Victoria Hospital
Montreal, Quebec

Pamela Wilton, RN
Vice President
Canadian Hemophilia Society
Montreal, Quebec

Additional Comments

From the Audience at the CHS/AHDC Conference May 25, 2007.

Geographic variations

There is a spectrum of different experiences by both patients and hemophilia healthcare providers across Canada. Centres outside urban areas are often smaller, while often also dealing with a large territory. In some rural areas, access to services such as accurate coagulation testing is difficult. Outreach and education is needed for hospitals in outlying and rural areas on the need to provide access to specialized 24-hour emergency care for bleeding disorders. The issues related to the country's vast geography need to be addressed in order to achieve national standards.

Safety and supply

The standards should clearly state that availability of safe and effective treatment products for all inherited bleeding disorders is essential.

Mobility

Canadians today travel more and more for education, social, recreational, or work purposes. The standards should address ensuring standards of care for children and adults with hemophilia and other inherited bleeding disorders when they move across different provinces for short- and long-term travel (e.g., coordination and liaison between clinics in different healthcare jurisdictions; travel notification by patients or caregivers). Communication about travels and continuity of service across regions is essential.

Details and ratios

The standards may be lacking in details and specific ratios, such as number of full-time equivalents in each area of expertise on the core team; the amount of protected time for hemophilia versus other bleeding disorders. It is essential to set out the human capital required to meet the standards. Specifying data, details, and ratios serves as a powerful advocacy and lobbying tool with government.

Age transitions

The standards also need to address continuity of patient care across transition periods, such as from pediatric to adult care or adult to elderly care. It is important to consider the role of HTC's in these different contexts.

Core team members

Family physicians should be included as members of the core team.

Evidence-based medicine

The standards document refers to the delivery of evidence-based patient care; however, much of the evidence is anecdotal at best.



Acknowledgments

Funding for the development of this document was provided unconditionally by Baxter Canada.