

## Progress and Lessons Learned

## Standards of Care for Hemophilia and Other Inherited Bleeding Disorders

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Toronto, November 14, 2009

# Previous milestones



1970s: Self/family administration of clotting factors  
(cryoprecipitate & concentrates)

# Previous milestones



Canadian Hemophilia Society  
Help Stop the Bleeding  
Société canadienne de l'hémophilie  
Arrêtons l'hémorragie

## L'hémophilie de nos jours



La société canadienne de l'hémophilie

*Les opinions exprimées ne reflètent pas nécessairement le point de vue de cette association.*

VOLUME 14, NUMÉRO 3

3ème TRIMESTRE, 1977

### L'Enquête Nationale: Rapport Préliminaire

Cet été, pendant une période de 14 semaines, 18 agents des services extérieurs et trois superviseurs régionaux se sont efforcés, à l'échelle du pays tout entier, non seulement de se mettre en rapport avec chaque hémophile recensé dans le district qui avait été confié à chacun d'entre eux, mais aussi d'obtenir l'adresse des hémophiles encore inconnus de la Société. Les travaux de vérification par recoupement des données ainsi rassemblées se poursuivent au moment de la rédaction du présent article.

La publication de "L'hémophilie de nos jours" a été retardée jusqu'à ce que quelques chiffres préliminaires aient pu être obtenus. D'après les prévisions, le prochain numéro devrait contenir un résumé du rapport officiel. Entre temps, on trouvera ci-après quelques statistiques exprimées en pourcentages et présentées selon trois types de classifications générales - à savoir par groupes d'âge (tranches de dix ans), par carences de divers facteurs, et en fonction de la répartition géographique.

| Pourcentages par Groupes d'âge |        |
|--------------------------------|--------|
| Moins de 10 ans                | 19.5   |
| 10-19                          | 35.7   |
| 20-29                          | 20.2   |
| 30-39                          | 10.9   |
| 40-49                          | 5.5    |
| 50 ans et plus                 | 8.4    |
| Tous les groupes d'âge         | 100.0% |

| Pourcentages par carence d'un facteur déterminé |      |
|---|------|
| Facteur VIII                                    | 57   |
| Facteur IX                                      | 14   |
| Maladie de Willebrand                           | 8    |
| Facteur XI                                      | 2    |
| Autre ou inconnu                                | 9    |
| Toutes les carences                             | 100% |

| Pourcentages par Provinces |        |
|----------------------------|--------|
| Colombie-Britannique       | 7.5    |
| Alberta                    | 6.3    |
| Saskatchewan               | 2.7    |
| Manitoba                   | 6.7    |
| Ontario                    | 38.7   |
| Québec                     | 21.8   |
| Nouveau-Brunswick          | 6.3    |
| Nouvelle-Ecosse            | 7.1    |
| I.P.E.                     | 1.4    |
| Terré-Neuve                | 1.6    |
| Canada                     | 100.0% |

Comme ces tableaux ont été établis sur la base de données préliminaires, il n'est pas possible de formuler ici des conclusions définitives. Toutefois, le rédacteur en

chef souhaiterait appeler l'attention sur certains chiffres en formulant, de sa propre initiative et sous sa propre responsabilité, les commentaires suivants:

1. Si nous supposons qu'il y a 15 hémophiles pour 100,000 habitants de sexe masculin et prenons pour base de calcul une estimation prudente du nombre de Canadiens de sexe masculin, soit 11 millions, nous pouvons considérer qu'il y a environ 1,800 hémophiles au Canada. Ce chiffre pourrait cependant être jugé trop faible (selon une étude effectuée aux États-Unis, il y aurait 25 hémophiles pour 100,000 habitants de sexe masculin). Comme le nombre d'hémophiles augmente (ce qui est dû en partie à une diminution du taux de mortalité infantile), on aurait peut-être intérêt à se montrer réaliste et à prévoir une stratégie permettant de satisfaire aux besoins futurs, en soins et en concentrés de plasma, d'une population hémophile qui, à l'heure actuelle, compte déjà plus de 2,000 individus.

2. Il semble que les trois quarts des personnes recensées sont âgées de moins de 30 ans. Mais cette estimation est, elle aussi, probablement inférieure à la réalité, car si le recensement indique que 36% des hémophiles sont âgés de 10 à 19 ans, il en découle que la proportion des sujets de moins de 10 ans, non encore diagnostiqués ou identifiés, est vraisemblablement supérieure aux 20% indiqués. D'un autre côté, il devrait être plus facile, pour diverses raisons, d'identifier le groupe composé des individus les plus âgés; par conséquent, la constatation selon laquelle ceux âgés de 50 ans et plus ne représentent que 8.4% de la population hémophile est à la fois intéressante et importante.

3. Les différences régionales ne méritent d'être considérées que si on établit une corrélation entre elles et la population de chaque province. Nous constatons cependant que, parmi tous les hémophiles recensés au Canada, plus de 6% vivent au Manitoba et en Alberta, tandis que moins de 3% se trouvent en Saskatchewan, et un tel écart ne saurait manquer d'intriguer les chercheurs.

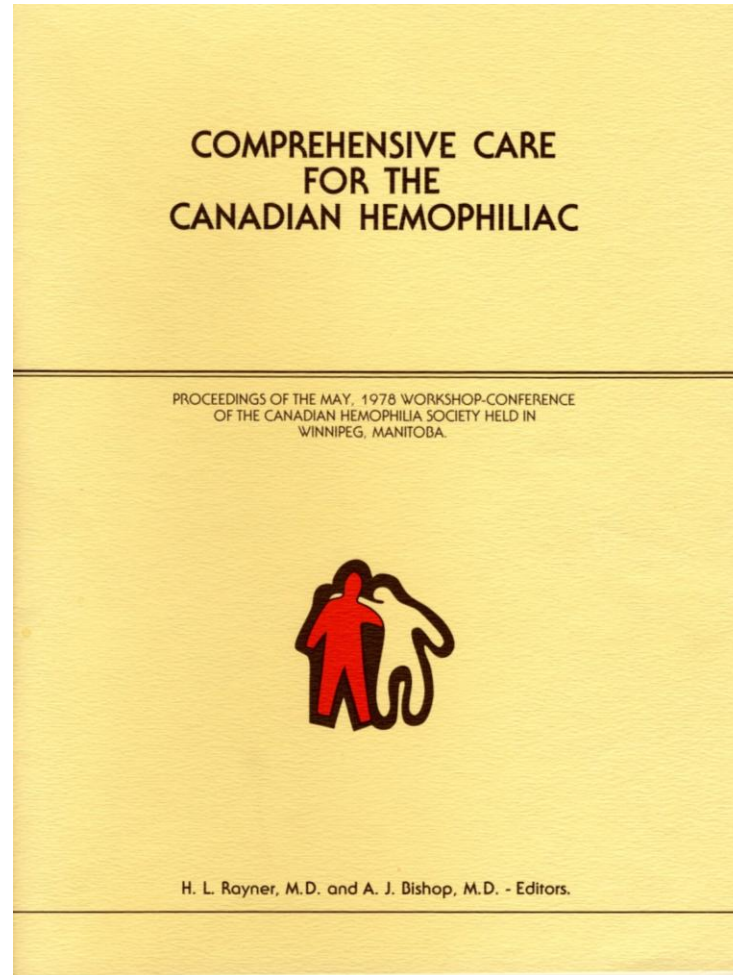
Tant que le rapport officiel n'aura pas été distribué, tout ce qui précède n'est que pure conjecture. Ces considérations relèvent néanmoins l'importance présentée par les données rassemblées par le Comité d'enquête, ainsi que les répercussions qu'elles auront en favorisant la création de centres de soins complets pour hémophiles, la fourniture de quantités suffisantes de concentrés de divers facteurs, et la dissémination de publications de vulgarisation par la Société.

#### Colloque de la Section de l'Alberta

Un colloque d'une journée a eu lieu à Edmonton le 9 septembre. Le Bulletin spécial annonçant cet événement précisait notamment ce qui suit: "Après six longues années de lutte menée afin d'obtenir des soins à domicile

1976: First Canadian Hemophilia Registry (managed by CHS)

# Previous milestones



1978: Winnipeg Conference to establish model for comprehensive hemophilia care

# Previous milestones



1980s:  
Creation of  
network of 25  
Hemophilia  
Treatment  
Centres in 9  
provinces

# Previous milestones



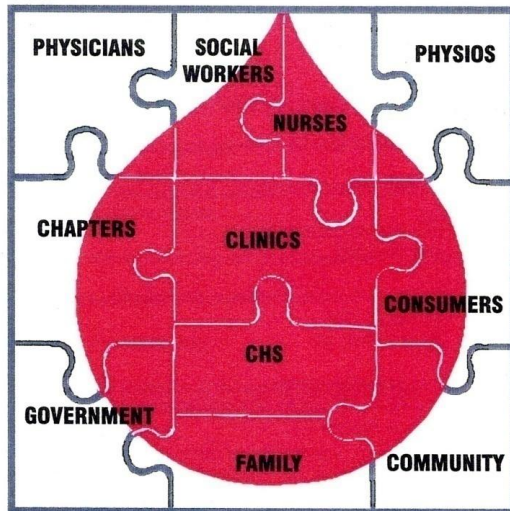
- 1990s: Creation of 4 professional groups
  - Association of Hemophilia Clinic Directors of Canada (AHCDC)
  - Canadian Association of Nurses in Hemophilia Care (CANHC)
  - Canadian Physiotherapists in Hemophilia Care (CPHC)
  - Canadian Social Workers in Hemophilia Care (CSWHC)

# Previous milestones

## WINNPEG II

### NATIONAL CONSENSUS CONFERENCE AND MEDICAL MEETINGS

April 29-May 2, 1998 • Winnipeg, Manitoba



Standards of Comprehensive Care  
for People with Hemophilia  
and Other Inherited Bleeding Disorders

Association of Hemophilia Clinic Directors of Canada

## 1998: Winnipeg II

A second conference to  
establish standards for  
hemophilia care

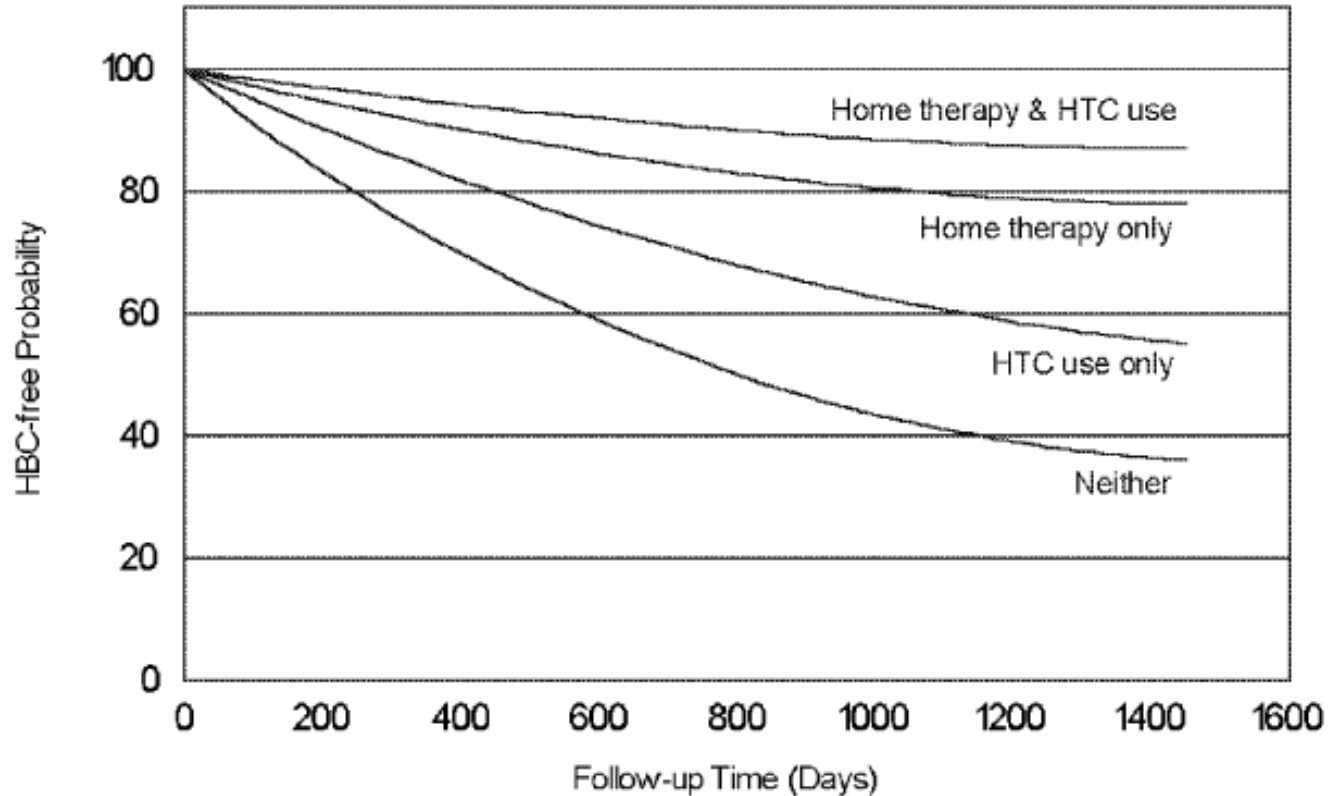
# Previous milestones



1999: Publication of *Clinical Practice Guidelines* for hemophilia and von Willebrand disease by Association of Hemophilia Clinic Directors of Canada

[www.ahcdc.ca/](http://www.ahcdc.ca/)

# Why standards?



**Fig. 1.** Chances of avoiding hospitalization for bleeding complications according to home therapy and haemophilia treatment centre (HTC) use among 2950 males with haemophilia identified by a six-state surveillance system and followed for up to 4 years. *Soucie et al, Haemophilia 7:198, 2001*

# Why standards?

|                | <i>Total</i> | <i>Deaths</i> | <i>Mortality Rate*</i> |
|----------------|--------------|---------------|------------------------|
| <i>Non-HTC</i> | 971          | 86            | 38.3                   |
| <i>HTC</i>     | 1979         | 149           | 28.1                   |

\* Deaths per 1000 person-years;  
*Soucie et al, Blood 2000; 96:437*

- 2004: AHCDC creates multi-disciplinary working group to develop standards
- 2007: First edition of standards is presented at AHCDC/CHS Medical and Scientific Symposium
- 2007: all 4 professional groups and patient organization endorse the standards document

# Previous milestones

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## CANADIAN COMPREHENSIVE CARE STANDARDS FOR HEMOPHILIA AND OTHER INHERITED BLEEDING DISORDERS

**First Edition**  
June 2007

Authored by the Canadian Hemophilia Standards Group<sup>1</sup>



<sup>1</sup> 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).

2007: Quebec City

Adoption of Canadian  
Comprehensive Care  
Standards for  
Hemophilia and Other  
Inherited Bleeding  
Disorders

## Aims

Intended for use by Hemophilia Treatment Centres, hospital administrations, and provincial Ministries of Health.

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.

## Focus of standards

On the *structural and resource requirements* necessary for a Hemophilia Treatment Centre to effectively provide care, and on its *functions and responsibilities*.

# Purpose of Standards

- Achieving recognition of Hemophilia Treatment Centres by hospital and provincial authorities
- 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
- Promoting discussion and research regarding optimal ways to deliver care
- Providing the basis for design of clinics, for accreditation, and for audit and evaluation

## Effective programs...

- deliver comprehensive care through an integrated, multi-disciplinary 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.

Scope of Care: To describe which bleeding disorders are to be addressed by the HTC, the required staff, and the administrative structure and responsibilities  
& Key Indicators

Quality Measures: To describe expected activities of an HTC that contribute to the quality of both the individual centre and the Canadian HTC network  
& Key Indicators

Therapeutic Services: To describe the actions required of an HTC in the direct delivery of therapeutic services  
& Key Indicators

# Scope of Care

1. Establish correct **diagnoses**.
2. Establish and maintain a full complement of **core team members**.
3. Develop **visibility**.
4. Strive to **enrol** all members of the target population.
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 and CHR databases.

# Scope of Care



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.
11. Have a **home infusion program**, including prevention and recognition of bleeds.
12. Provide **prophylaxis** regimens.
13. Provide **early intervention** and follow-up care to reduce long-term complications.
14. **Network** with outside agencies.
15. Encourage & facilitate eligible members to participate in **professional activities**.

1. Participate in **data collection** and submission to CHARMS including patient demographics and factor utilization.
2. Maintain **health records** according to legislation.
3. Submit **anonymous data** to the *Centre Point* module of CHARMS and to the CHR.
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.
7. Participate in a formal **accreditation** and evaluation process once it is established.
8. **Mentor**, where possible, students and trainees in the health professions.
9. Establish mechanisms to acknowledge and review compliments, **complaints** and special requests.

1. Provide the appropriate **professional care**.
2. Provide a comprehensive **assessment** at least annually for adult patients and semi-annually for children.
3. Provide **assessments** from each core team member at least annually.
4. Provide **emergency departments and family physicians** with diagnosis and treatment recommendations. Arrange for qualified **24-hour medical coverage** and consultative services.
5. Educate patients and families on the best way to advocate for and to access **emergency care** and other services.
6. Utilize **clinical practice guidelines** published by AHCDC and other expert bodies.

7. Establish **formal links** to provide access to special hemostasis testing, genetic testing, and treatment.
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.
10. Provide **prophylaxis** to patients in accordance with AHCDC recommendations and best practice.
11. Provide a **home therapy program** to all appropriate patients and monitor its effectiveness.

12. Provide **injection equipment** and other supplies to patients.
13. Provide management for patients with **inhibitors**.
14. Be located in a facility that should be readily **accessible**.
15. Be located within an **Ambulatory Clinic area** to facilitate prompt assessment and treatment.
16. Be located in a facility that has or is **linked with an Emergency Department** where patients can obtain treatment outside of regular hours.

# Full Standard

- The full standard, including performance indicators, is available at:

[www.hemophilia.ca/en/care-and-treatment/comprehensive-care-standards/](http://www.hemophilia.ca/en/care-and-treatment/comprehensive-care-standards/)

# Subsequent Steps

- 2008: Development of an anonymous, voluntary self-administered survey for HTC's based on the standards
- Spring 2009: Survey carried out in 23 of 25 HTC's
- Autumn 2009: Results collated and analyzed
- 2010: Standard revised (if necessary)
- 2010: Creation of external audit process
- 2010: First audits of HTC's
- 2011-2013: Rollout of audit process across Canada

# Canadian Hemophilia Standards Group



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CSWHC