A National Assessment of Hemophilia/Inherited Bleeding Disorder Comprehensive Care Program Services and Resources

prepared by the

Canadian Hemophilia Society
Help Stop the Bleeding

Société canadienne de l'hémophilie
Arrêtons l'hémorragie

May 2015
“Penny wise, pound foolish”

An old English expression...

“to be extremely careful about small amounts of money and not careful enough about larger amounts of money”

- Cambridge Dictionaries Online
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May 2015
Section A: Executive Summary

In 2013-14, the Canadian Hemophilia Society (CHS) conducted an assessment of the human and physical resources in the network of 25 Inherited Bleeding Disorder Comprehensive Care Centres (IBDCCCs) across Canada. The staff in these Centres care for the vast majority of Canadians with inherited bleeding disorders. Our goal was to evaluate their capacity to respect current national Standards of Care. Individual reports were provided to each Program’s Centre Director. This national report summarizes the findings and presents key recommendations.

The CHS discovered that, despite dedicated and well-trained staff, the Programs are experiencing serious resource deficiencies. Twenty-three of the 25 Programs lack human resources in one or more of the following disciplines: hematology, physiotherapy, social work, clerical/data entry and nursing. In nine of the 25 Programs, no resources are allocated to certain core disciplines, notably physiotherapy and social work. The level of resources varies widely and inexplicably from Program to Program: from 0.2 to 1.5 Full Time Equivalents (FTEs) per 100 hemophilia A and B patients in nursing; from 0 to 0.4 FTEs per 100 patients in physiotherapy and social work, and 0 to 1.8 FTEs in clerical/data entry. Because of lack of clinic time or physical space, nine of the 25 Programs are unable to respect the schedule for regular health assessments as prescribed in the Standards of Care.

The cost to deliver care (including the cost of staffing, diagnostic and clinical support services, non-labour costs and office space, but excluding the cost of coagulation therapies) to the approximately 10,000 patients registered in IBDCCCs in Canada is estimated at approximately $20,000,000 (1). Many Programs are subject to increasing hospital, regional health authority or Ministry of Health pressures to limit or even reduce existing resources, despite a 75% increase in the number of patients registered in the 25 Programs in the period 2004-2014 (2) and increasing demands on services, in part because of an aging population. Only a few provinces have given provincial designation to their Programs for these rare inherited bleeding disorders (disease incidence of 1 in 10,000 to 1 in 1,000,000) requiring specialized and expert care. Budget restrictions at the Program level are viewed by the CHS as “penny-wise.”

The cost of coagulation therapies (factors I, II, VII, VIII, IX, XI, XIII, VIII/VWF and factor VIII bypassing therapies) in 2013-14 was $204,000,000 for Canadian Blood Services (3) and $46,000,000 for Héma-Québec (4) for a total of $250,000,000, despite a significant decrease in the per unit cost of recombinant factor VIII—factor VIII represents close to 50% of the total coagulation factor budget—compared to previous years (5). Prescription of these biological products requires the expertise of hematologists experienced in the care of people with inherited bleeding disorders, expertise and experience that resides only in physicians working in IBDCCCs. Approximately ninety percent of these products are infused by patients and their caregivers via home infusion programs to prevent bleeding, a Standard of Care for many patients in Canada and around the world for the last several decades (6). Many Programs, however, describe a lack of capacity to adequately monitor the optimal utilization of these clotting factor concentrates used in home infusion protocols and their key clinical outcomes. Systems to report home infusions in accurate and timely ways are inadequate. Data entry resources cannot react to or solve any identified problems with the actual data entry process. Nurses are unable to respond quickly to critical care issues as identified by accurate and timely reporting of factor utilization. Under- and over-utilization occur. Sub-optimal health outcomes, including unnecessary bleeding and joint damage, are the results. Product wastage occurs in such an environment.
The cost of coagulation therapies, therefore, represents 90 to 95 percent of the total costs for the care of people with bleeding disorders. A silo approach to funding the care of people with inherited bleeding disorders is a barrier to rational resource allocation; hospitals are unaware of and perhaps unconcerned with the cost of factor concentrates reimbursed via the provincial blood budgets, and Ministries of Health have little control over hospitals’ human resources. The CHS views the current under-funding of Programs, whose role is to facilitate the best health outcomes with such valuable coagulation therapies, as “pound-foolish.”

Why is this a critical time to correct the problems?

A key indicator of the level of hemophilia care in a country is the number of International Units (IUs) of factor VIII consumed per capita. Canada currently uses 5.7 IUs per capita, 25-50% less factor VIII than developed countries such as United States, United Kingdom, Australia, Ireland and Sweden (7), in part due to historically conservative prophylactic protocols. In Canada over the last five years, utilization of factor VIII has been increasing at a rate of 6% per year (8). The recent 40-50% decrease in the per unit cost of factor VIII in Canada is very likely to be accompanied by an increase in utilization, as patients and physicians adopt prophylactic regimens that more effectively protect against bleeding and improve quality of life. At the same time, extended half-life factor VIII and IX concentrates, the first advance in the efficacy of factor therapies in four decades, are being introduced. The abilities to document utilization and evaluate health outcomes as clinical practices evolve are more critical than ever. This can only be done with adequate human resources in the Centres.

Moreover, to facilitate infusion reporting, data collection and health outcome research, the Association of Hemophilia Clinic Directors of Canada and McMaster University are launching the Canadian Bleeding Disorder Registry (CBDR) across Canada in 2015 to replace the outdated Canadian Hemophilia Assessment and Resource Management System (CHARMS). This information system has the potential to significantly improve home infusion reporting, data collection, health monitoring by Centre staff, patient decision-making, and health outcome research across the country and internationally. It will attain these goals, however, only if the CBDR is adequately funded in the medium to long term. The cost, including data entry resources in the Centres, is estimated at $600,000-$700,000 per year (9), or approximately one-quarter of one percent (0.25%) of the cost of coagulation therapies. Resources for accurate and timely data entry must be available in the 25 IBDCCCs; proper implementation of CBDR depends on it.

The centre assessments revealed that 52.2 FTEs are currently funded in the core disciplines of nursing, physiotherapy, social work and clerical/data entry across Canada. An additional 21.1 FTEs are considered necessary to help Program staff meet the current challenges of increasing numbers of patients and respect Standards of Care. At an average of $70,000 per FTE, this represents a national investment of less than $1,500,000, or approximately one-half of one percent (0.5%) of the current total budget of $270,000,000 for the care of people with inherited bleeding disorders.

Despite these shortcomings, it must be said patients and their families express very strong appreciation for the competence and dedication of the health care providers who work in the 25 IBDCCCs across Canada, and for the comprehensive care model that has evolved over the last four decades.
KEY RECOMMENDATIONS

1. That health officials in the provinces and territories consider the results of the individual Centre assessment reports and adjust human and physical resources in IBDCCCs so that Standards of Care can be respected and optimal care provided. Of paramount importance are the core team disciplines: physiotherapy, social work, administration/data entry, pediatric and adult physician, nursing.

3 & 4. That the provinces and territories support the medium and long-term operational costs of the Canadian Bleeding Disorder Registry so that utilization of coagulation therapies can be effectively monitored, individual patient care improved and overall health outcomes evaluated; That hospitals, regional health authorities and Ministries of Health (as appropriate) provide sufficient resources in data entry/management so that the Canadian Bleeding Disorder Registry can be used to its full potential.

11. That Inherited Bleeding Disorder Comprehensive Care Centres be recognized by Ministries of Health as having provincial mandates and that provincial or designated envelope funding be provided (where this is not already the case).

13. That IBDCCCs be given a provincial mandate for the prescription of clotting factor concentrates such that, except in emergency, they can only be prescribed to patients registered in a Program; and that outlying hospitals that distribute clotting factor concentrates be required to report distribution to the Program (where this is not already the case).

16. That IBDCCCs and the hospitals that house them support professional training and continuing education for core team members for these rare conditions through their national associations, namely: Canadian Association of Nurses in Hemophilia Care, Canadian Physiotherapists in Hemophilia Care and Canadian Social Workers in Hemophilia Care.

ALL 25 RECOMMENDATIONS CAN BE FOUND IN SECTION F.
Section B: Introduction

Comprehensive care

In Canada, the minimum standard of care for patients with inherited bleeding disorders is known as comprehensive care. Comprehensive care is principally delivered by a specialized interdisciplinary team to ensure accurate diagnosis; early and adequate factor replacement for bleeding episodes; “prophylaxis” or regular factor administration to prevent joint bleeding and preserve joint health; long-term management of joint and muscle damage and other sequelae; psychosocial support and education required to manage the bleeding disorder; and management of treatment associated complications. The latter can include the development of “inhibitors”, antibodies that interfere with the function of the transfused coagulation factor, and/or chronic infections acquired through contaminated blood products. Core members of the specialist interdisciplinary team include:

- Physicians – pediatric and adult hematologists with additional training in the management of inherited bleeding disorders who provide medical oversight of care and provide expert advice to physicians province-wide.
- Clinical Nurse Specialist and Patient/Nurse Educator – advanced nursing care to individuals/families including teaching, case management and supporting patients in assessment of bleeds, navigating the health system with a bleeding disorder, home intravenous administration of factor and management of preventative doses of factor around major and minor procedures.
- Physiotherapist – with additional musculoskeletal training or experience has an active role in assessment of chronic joint health, bleeds and peri-operative recovery to promote optimal joint health, minimize disability and improve quality of life.
- Social Worker – to offer assessment, intervention and evaluation of psychosocial issues and support patients in managing the complexities of work, school, immigration or travel with a bleeding disorder. They play a major role with patients transitioning, securing financial resources to assist with travel, clinic attendance and other complexities such as compensation for HIV and hepatitis C infected patients.
- Administration/data entry – to provide clerical support to the comprehensive care team and record data related to the home use of clotting factor concentrates, including product utilization and key clinical outcomes.

Comprehensive care has been shown to reduce disease and treatment-associated morbidity and mortality. The minimum comprehensive care standard for adults is one clinic visit per annum as well as ongoing timely access to the care team as needed throughout the year. The standard for pediatric patient assessments is twice per annum.
Hemophilia and other inherited bleeding disorders

Bleeding disorders can be divided into four categories.

**Hemophilia A and B**

Hemophilia A and B are both lifelong, hereditary disorders caused by deficiencies in the specific blood proteins factor VIII or IX. In 1 out of 3 cases, there is no history in the family; the cause is a new genetic mutation. Thus hemophilia can affect any family. The two types of hemophilia, A and B, affect 3800 Canadians.

The blood of people with hemophilia doesn’t clot normally; they don’t bleed more profusely or more quickly than others ... but for a longer period if not treated. External wounds are usually not serious. Far more important is internal bleeding into joints and muscles. Untreated, this is excruciatingly painful and leads to severe crippling. When bleeding occurs in a vital organ, especially the brain, it can be fatal. Where treatment is unavailable, life expectancy is less than 20 years. Today, with access to an optimal supply of clotting factor concentrates and excellent comprehensive care, young people with hemophilia can look forward to life expectancy very close to normal and full integration into society.

Hemophilia is an X-linked genetic disorder; therefore, the most severe forms of hemophilia affect almost only males. Women who are carriers, however, often have mild symptoms and can have bleeding problems that affect their quality of life.

In about 30% of people with severe hemophilia, the immune system rejects the clotting factors infused to stop or prevent bleeding. In one-third of these cases, this complication, called an inhibitor, is persistent, very serious and can be life-threatening.

The cost of clotting factor concentrates to treat hemophilia A and B in Canada in 2013-14 was close to 215 million dollars.

**Von Willebrand disease (VWD) ... the most common inherited bleeding disorder**

One in 100 Canadians (300,000 people) carries the gene for von Willebrand disease. Symptoms affect an estimated 30,000 Canadians, both male and female. Many of these people have yet to be properly diagnosed; just over 4,000 are registered in IBDCCCs. Life-threatening hemorrhaging can occur after childbirth, surgery or trauma.

A woman’s quality of life can be more seriously affected. Heavy menstrual bleeding can lead to hysterectomies. These can be avoided if the woman is properly diagnosed and treated.

Effective treatments, both plasma-derived clotting factor concentrates and chemical drugs, are available for von Willebrand disease.

The cost of von Willebrand factor concentrates in 2013-14 was approximately 28 million dollars.

**Rare factor deficiencies**

A small number of Canadians, fewer than 1500, suffer from rare factor deficiencies. These people have low levels of a specific blood protein, either factor I, II, V, VII, X, XI, or XIII. Like hemophilia and VWD, these are genetic conditions for which there are treatments in the form of clotting factor concentrates, but no cures. The cost of factor concentrates to treat rare factor deficiencies in 2013-14 was approximately seven million dollars.

**Platelet function disorders**

There are many different kinds of inherited platelet function disorders. In these disorders, blood platelets do not function normally, resulting in blood not clotting properly. In some
individuals, bleeding can be severe. Some people have no symptoms at all until they have a serious injury or surgery. As with von Willebrand disease, many cases go undiagnosed for decades.

More than 10,000 people with inherited bleeding disorders are registered in Canada’s 25 inherited bleeding disorder comprehensive care centres (IBDCCCs).

Canadian Hemophilia Society

The Canadian Hemophilia Society (CHS) was founded in Montreal in 1953 by a small group of people with hemophilia, their families and physicians. Their dream at the time was to improve the quality of life and find a cure for hemophilia. The close collaboration among patients, health care providers and researchers was unique then and provides a model for the health care field today.

Through their efforts, the CHS quickly developed from a small, Montreal-based support group to a national volunteer patient organization.

Today, the Canadian Hemophilia Society is a national not-for-profit health charity, governed by a volunteer Board of Directors. Its national headquarters are in Montreal. The CHS has 10 autonomous provincial chapters, each with a volunteer Board of Directors. There are provincial chapter offices in three provinces: Quebec, Ontario and Manitoba. The CHS and its chapters have approximately 300 active volunteers and 20 staff across the country. The CHS is affiliated with the World Federation of Hemophilia, which is officially recognized by the World Health Organization.

The CHS provides programs and services to people with hemophilia A and B, von Willebrand disease, rare factor deficiencies and inherited platelet disorders, and to the health care providers who care for them.

The Canadian Hemophilia Society has five strategic priorities:

Care and Treatment – The CHS works in close collaboration with medical professionals—physicians, nurses, physiotherapists, social workers, and other related specialists—in the 25 specialized bleeding disorder treatment centres across the country. Our common goal is to ensure optimal inter-disciplinary care and treatment for all members of the family. We define this as comprehensive care.

Research – The CHS provides basic and clinical research grants and research fellowships to fund leading Canadian researchers working in the field of bleeding disorders in an effort to improve care and treatment, and ultimately find a cure.

Support and Education – The CHS is the primary source of educational materials designed for people with bleeding disorders, their families, health care professionals and the general public, and is world renowned for the quality of its programs and publications. Our website is recognized as the most comprehensive in the world.

Safe, Secure Supply of Therapies – In the 1970s and 1980s, 700 Canadians with hemophilia were infected with HIV from tainted blood. Two-thirds of these people have passed away. In addition, 1600 were infected with hepatitis C. The CHS played a key role in building a safer blood system for Canadians, leading to the creation of Canadian Blood Services and Héma-Québec. The CHS continues to be vigilant as the watchdog of the blood system on behalf of all Canadians. CHS experts serve on Canadian Blood Services and Hema-Quebec committees, provincial blood advisory committees, and monitor blood safety nationally and internationally.
The CHS receives program funding from all the companies in the Canadian clotting factor concentrate market. Our relationship with them is carefully regulated by our Policy on Relationships with Companies in the Pharmaceutical Industry, which is guided by best ethical practices. The CHS also receives significant donations and bequests from members of the general public and is one of 16 members of Healthpartners, a federal government workplace giving program. While the national organization receives no government funding, two of our chapters, Quebec and Ontario, receive provincial supporting grants.

Context

In June 2007, after a lengthy process led by the multi-disciplinary Canadian Hemophilia Standards Group, a document entitled Canadian Comprehensive Care Standards for Hemophilia and Other Inherited Bleeding Disorders (see Annex 4), based on work done in Ontario, was adopted by the four health care provider associations whose members make up the core teams in hemophilia / inherited bleeding disorder programs: the Association of Hemophilia Clinic Directors of Canada (AHCDC), the Canadian Association of Nurses in Hemophilia Care (CANHC), the Canadian Physiotherapists in Hemophilia Care (CPHC) and the Canadian Social Workers in Hemophilia Care (CSWHC), and the national patient organization, the Canadian Hemophilia Society. The focus of these standards is on the structural and resource requirements necessary for a Hemophilia Treatment Centre (HTC) to effectively provide care, and on its functions and responsibilities.

In May 2010, the Canadian Hemophilia Standards Group published the results of a self-assessment survey conducted by 24 of the 25 IBDCCCs to validate the standards (10). The general level of acceptability of the standards was found to be high and it was concluded that they could be used for the purpose of external accreditation.

An external accreditation process, based on the audit processes developed by the United Kingdom Haemophilia Centres’ Doctors Organization and the Irish Haemophilia Council, was developed by the Canadian Hemophilia Standards Group in 2011, but never implemented.

In 2013, considering the absence of a timetable to pursue a formal accreditation process, the Canadian Hemophilia Society developed its own assessment process. The overall goal is to identify any gaps in resources that may prevent IBDCCCs from delivering care and treatment according to the adopted Standards and that may lead to poor/sub-optimal patient outcomes. IBDCCC participation in the process was supported by the AHCDC. The primary objectives were to:

- Conduct a thorough assessment of the services and resources in Hemophilia Treatment Centres in each province;
- Prepare a detailed report and recommendations for hospital administrators and/or Ministry of Health officials in each province;
- Identify and meet key decision-makers in each province with the goal of maintaining and improving the care for people with inherited bleeding disorders;
- Follow up to push for implementation.
Methodology

The assessment is in two parts:

- interviews with core members of the comprehensive care team, either individually or in groups (see Annex 1), based on a questionnaire developed in 2011 by the Quebec Chapter of the Canadian Hemophilia Society and used to assess the four Quebec HTCs;

- a patient satisfaction survey, developed by the Canadian Hemophilia Standards Group for the accreditation process. A slightly modified version of the survey was used successfully in 2013 by the Irish Haemophilia Council in its audit of IBDCCs in Ireland. A random selection of 3000 patients who had been seen in clinic in the last two years was made using the Canadian Hemophilia Registry (CHR) database. Questionnaires were sent by mail to the Centre staff. Answers were returned to the Canadian Hemophilia Society for compilation. Responses were anonymous. Twenty of the 25 Canadian centres distributed the patient satisfaction survey. Due to problems with CHR identifiers and varying degrees of participation by hemophilia / inherited bleeding disorder programs, it is not possible to state with any accuracy the number of questionnaires distributed; however, 347 were completed and received by the CHS. (See complete national results in Annex 2.)

The methodology is limited in that the assessors, for reasons of confidentiality, had no access to patient records and could not independently verify key indicators such as, for example, the capacity of the Programs to provide semi-annual or annual assessments as per the Standards. Concordance between the information provided by the Centre staff and the responses collected through the patient survey, however, often overcame this limitation.

Participation

The participation of the centres was entirely voluntary. The four Quebec centres participated in the assessment in 2011 and it was not considered necessary to repeat the process in 2013-2014. Of the remaining 21 centres in the rest of Canada, 19 accepted to participate fully. One declined. In the remaining centre, only the adult hematologists could be interviewed. The patient satisfaction survey was, however, distributed. All 25 centres provided up-to-date information on the numbers of patients registered and on the staffing levels of core team members.

The visits to the centres occurred between October 2013 and July 2014. Draft reports were prepared and returned to the centre directors for review and validation. Final reports were distributed to centres between October 2014 and April 2015.

Assessors

The assessors were David Page, national executive director, Canadian Hemophilia Society; Sarah Crymble, Ontario hemophilia provincial coordinator; and Michel Long, national program manager, Canadian Hemophilia Society. Guidance and input on the assessment process was provided by Pam Wilton, RN, past-president of the Canadian Hemophilia Society and Board member of the World Federation of Hemophilia. (See Annex 3 for biographies.)
Section C: Numbers of patients

Table 1 lists the numbers of patients by disease condition as reported by each of the 25 Programs between October 2013 and July 2014. These numbers are very similar to the data provided by the Canadian Hemophilia Registry in May 2014 to the World Federation of Hemophilia Global Survey (11).

Table 1: Numbers of bleeding disorder patients

<table>
<thead>
<tr>
<th>Disease Condition</th>
<th>Severe</th>
<th>Moderate</th>
<th>Mild</th>
<th>Inhibitors</th>
<th>Other*</th>
<th>Total</th>
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</thead>
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<tr>
<td>Hemophilia A</td>
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* Acquired, unclassified, carriers, referrals
Section D: Key observations by health care providers

1. The strengths of the Programs

The staff identified the following key strengths of the 25 Programs (the numbers in brackets indicate the number of Programs that made the same observation):

**Human resources**
- Committed, cohesive, stable and well-trained inter-disciplinary teams that have developed longitudinal experience and knowledge of patients, and that communicate well with each other; (16)
- A full complement of core team members; (6)
- A sufficient number of hematologists, providing flexibility and back-up; (4)
- Nurse practitioners as part of the team; (2)
- Flexibility in the nurses' work schedules to accommodate patient schedules, urgent care and support for surgical procedures; (2)
- Inclusion of an obstetrician-gynecologist and dentist as extended team members; (1)
- A designated physiotherapist; (1)
- Weekly meetings of the team; (1)
- Excellent support from managers; (1)
- Capacity to attend summer camp as part of job description. (1)

**Services**
- A sufficient number of clinics to assess patients every 3, 6, 12 or 24 months, according to the Comprehensive Care Standards for Hemophilia and Other Inherited Bleeding Disorders; (9)
- A strong home care program with re-certification that reduces in-patient and Emergency Department visits to a minimum; (8)
- Ability to participate in the Canadian Hemophilia Surveillance System (CHESS) and conduct high-level pre-clinical and clinical research; (8)
- An integrated pediatric-adult program and seamless transition for patients graduating from pediatric to adult care; (7)
- The capacity to hold travelling clinics in other centres; (6)
- An 18/7 or 24/7 nursing on-call system; (4)
- 24/7 coverage by the on-call hematology/oncology team; (4)
- A strong capacity to work with the recent immigrant population and the special needs they present to the Program; (4)
- Daily access to nursing care at the Centre; (2)
- Very short wait times for new patients referred to the Program; (2)
- A monthly Women and Bleeding Disorder clinic with OB-GYN expertise; (2)
- A patient-centered service; (1)
- Excellence in therapeutic services; (1)
- Good rapport with patients; (1)
- Very close follow-up with patients; (1)
- Having pediatric care and the women’s program in the same building; all the subspecialties are at hand; (1)
- A genetic counseling service; (1)
- A strong investment in newborns and very young children, which research has shown to be a key to preventing joint damage in later life; (1)
- A psychologist able to provide support for issues of stress and chronic pain, and to promote adherence to treatment protocols; (1)
- Copies of clinic letters sent to families/patients to reinforce treatment; (1)
- Saturday clinics for out-of-towners; (1)
- Genotyping of 100% of patients; (1)
- The capacity to treat infectious disease (HIV, HCV) complications of past clotting factor treatment; (1)
- Experience in immune tolerance induction therapies; (1)
- Success in working with patients to generate accurate home infusion records; (1)
- Capacity to conduct Saturday or after-school educational sessions with young patients. (1)

**Physical and information resources**
- Excellent space for treatment rooms in the Centre or an excellent dedicated clinic space; (5)
- Good physical space for offices in proximity to clinic space; (4)
- A fully deployed Electronic Patient Record; (4)
- Access to a 24/7 hematology out-patient clinic that provides emergency care out-of-hours, and helps to avoid recourse to the Emergency Department; (3)
- Ability to use Telemedicine to diagnose and treat acute bleeds in patients in remote locations; (3)
- On-line information on both the pediatric and adult programs, including location; (3)
- Easy access for patients to the clinic (drop-off at door); (2)
- Up-to-date manuals to promote quality assurance. (2)

**Training, Continuing Education**
- Ability to attend regional and national meetings of professional associations to share best practices (medical, nursing, physiotherapy, social work); (13)
- Involvement with national professional associations (medical, nursing, physiotherapy, social work). (9)

**Relationships, outreach**
- Capacity to liaise with and do outreach to other health care providers and Emergency Departments at other hospitals; (12)
- Good relationships with and a well-functioning hemostasis lab; (8)
- Good working relationship with the CHS Chapter; (7)
- Good access to and support from other health care services and hospitals; (6)
- In-service training by bleeding disorder nurses for in-patient care and in the Emergency Department; (6)
- Capacity to do outreach to schools; (3)
- Close working relationship/communications with the adult Program; (1)
- Treatment instructions for all patients coming to Emergency. (1)
Funding
- Designated provincial funding; (2)
- Funding for patients to attend clinics; (2)
- Access to a fund (through industry and the local chapter of the CHS) for certain patient supplies. (1)

2. The weaknesses of the Programs
The staff identified the following areas that need to be addressed to best meet the Standards:

Human resources
- Serious lack of adequate human resources, vulnerability to hospital-level decisions; (23)
- Insufficient or no dedicated time for the social work position; (19)
- Physiotherapy position not adequately funded; (17)
- Insufficient or no dedicated time for administration / data entry; (15)
- FTE in nursing is insufficient; (13)
- Core team is incomplete; (9)
- Difficulty with staff retention; (1)
- No dentistry; (1)
- No psychologist; (1)
- No access to pain specialist; (1)
- Sub-speciality support is deficient: the Program has no dedicated rheumatologist, orthopedic surgeon or dentist. (1)

Services
- Insufficient clinic time (usually adults); (9)
- Lack of resources to follow up on home infusion diaries; (6)
- No capacity to conduct outreach clinics; (4)
- Restrictions on testing in coagulation lab on weekends; (3)
- Lack of involvement in national research to assess health outcomes; (3)
- No specialized clinic for women with bleeding disorders with an assigned obstetrician-gynecologist; (2)
- Clinic inaccessible from 9 to 5; (1)
- Lack of 24/7 access to Centre personnel; (1)
- Lack of capacity to follow schedule of annual, semi-annual and quarterly who cannot come to centre or attend travelling clinics; (1)
- Lack of support for patients to travel; (1)
- A long waiting list for assessment and surgery; (1)
- Need for improvement in transitioning teens; (1)
- Inability to conduct home visits to do education about home infusion; (1)
- No oral surgeon serving the Program; (1)
- An inability to follow mild patients treated in the community and who are not registered in the treatment centre. (1)
Physical and information resources
- Insufficient, inadequate clinic space (usually adults); (9)
- Information technology; (8)
- Lack of robust quality assurance programs, written policies and procedures for assessing patients are lacking; (7)
- Need for more efficient data entry of patient care information; (4)
- Need for more on-line information on Program and to direct patients to the Centre; (3)
- Office space not optimal; (2)
- Lack of tools (such as GRASP) to help track workload; (1)
- Program can no longer supply infusion equipment. (1)

Training, Continuing Education
- Core team members not supported in pursuing continuing education, largely through meetings of their national associations. (4)

Relationships, Outreach
- Lack of visibility within the hospital and with health authorities, no provincial recognition; (4)
- Transition program difficult to coordinate through two different health authorities; (1)
- Decreasing support from chapter, especially in terms of effective advocacy; (1)
- Not all VWD patients are referred to the Program. (1)

Funding
- Need for increased support from the chapter to help patients (e.g. financial support to attend clinic). (1)

3. Human resources

Current levels
Following consultation with experts in the IBDCCCs, the number of hemophilia A and B patients in a centre was chosen as the best criterion for comparing staffing levels. All people with hemophilia A and B, whether severe, moderate or mild, are very likely to be diagnosed and followed in an IBDCC. It was decided to give the same weight in this calculation to each patient, independently of the burden of severe disease, the presence of inhibitors, infectious disease complications or pediatric status. Policies on registration of patients with von Willebrand disease, on the other hand, are quite variable from Program to Program and made their total numbers a less reliable benchmark. Other factor deficiencies are exceedingly rare and even more variable from centre to centre.

Table 2 lists the full-time equivalent (FTE) positions for the four core program disciplines of nursing, physiotherapy, social work and administration/data entry in the 25 IBDCCCs per 100 hemophilia A and B patients. Centres 1 to 5 are pediatric Programs; Centres 6 to 10 provide services only to adults; Centres 11 to 25 are Programs that serve pediatric and adult populations with the same core team.
**Table 2: Full-time equivalents (FTEs) per 100 hemophilia A and B patients in all centres**

<table>
<thead>
<tr>
<th>Centre</th>
<th>Nursing</th>
<th>Physiotherapy</th>
<th>Social work</th>
<th>Admin/data</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1.5</td>
<td>0.4</td>
<td>0.3</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>1.0</td>
<td>0.2</td>
<td>0.3</td>
<td>0.6</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>1.0</td>
<td>0.3</td>
<td>0.2</td>
<td>0.14</td>
<td>These are pediatric centres</td>
</tr>
<tr>
<td>4</td>
<td>0.9</td>
<td>0.1</td>
<td>0.2</td>
<td>1.1</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>1.6</td>
<td>0.4</td>
<td>0.4</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>0.6</td>
<td>0.2</td>
<td>0.2</td>
<td>0.2</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>0.6</td>
<td>0.1</td>
<td>0.1</td>
<td>0.6</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>0.4</td>
<td>0.1</td>
<td>0.01</td>
<td>0.2</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>0.4</td>
<td>0</td>
<td>0</td>
<td>0.2</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>0.6</td>
<td>0</td>
<td>0.1</td>
<td>0.1</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>1.2</td>
<td>0.14</td>
<td>0.2</td>
<td>0.5</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>0.5</td>
<td>0.2</td>
<td>0.05</td>
<td>0.6</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>0.8</td>
<td>0.2</td>
<td>0.3</td>
<td>0.8</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>0.5</td>
<td>0.1</td>
<td>0.1</td>
<td>0.6</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>1.5</td>
<td>0.25</td>
<td>0.1</td>
<td>0.4</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>0.6</td>
<td>0.1</td>
<td>0.05</td>
<td>0.01</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>1.0</td>
<td>0.1</td>
<td>0</td>
<td>0.6</td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>1.3</td>
<td>0</td>
<td>0</td>
<td>0.6</td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>1.4</td>
<td>0.4</td>
<td>0.4</td>
<td>1.8</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>1.0</td>
<td>0.05</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>0.6</td>
<td>0.1</td>
<td>0</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>1.0</td>
<td>0.25</td>
<td>0.02</td>
<td>0.25</td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>1.1</td>
<td>0.07</td>
<td>0.07</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>0.2</td>
<td>0.01</td>
<td>0.01</td>
<td>0.1</td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>0.4</td>
<td>0.01</td>
<td>0</td>
<td>0.4</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>21.7</strong></td>
<td><strong>3.88</strong></td>
<td><strong>3.11</strong></td>
<td><strong>12.36</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Mean</strong></td>
<td><strong>0.87</strong></td>
<td><strong>0.15</strong></td>
<td><strong>0.13</strong></td>
<td><strong>0.47</strong></td>
<td></td>
</tr>
</tbody>
</table>

To compare centres of similar size and with similar populations, the 25 IBDCCCs were divided into five categories:
- the five pediatric centres
- the five adult centres
- the five largest combined pediatric/adult centres
- the five medium-sized combined pediatric/adult centres
- the five smallest combined pediatric/adult centres.

Their ratios of FTEs to 100 hemophilia A and B patients are presented in Table 3.
Table 3: Comparison of full-time equivalents (FTEs) per 100 hemophilia A and B patients by category of centre

<table>
<thead>
<tr>
<th></th>
<th>Nursing</th>
<th>Physiotherapy</th>
<th>Social work</th>
<th>Admin/data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatric centres</td>
<td>1.20</td>
<td>0.30</td>
<td>0.30</td>
<td>0.57</td>
</tr>
<tr>
<td>Adult centres</td>
<td>0.50</td>
<td>0.08</td>
<td>0.08</td>
<td>0.26</td>
</tr>
<tr>
<td>5 largest combined centres</td>
<td>0.82</td>
<td>0.15</td>
<td>0.06</td>
<td>0.47</td>
</tr>
<tr>
<td>5 medium-sized centres</td>
<td>1.1</td>
<td>0.17</td>
<td>0.13</td>
<td>0.68</td>
</tr>
<tr>
<td>5 smallest combined centres</td>
<td>0.74</td>
<td>0.05</td>
<td>0.06</td>
<td>0.38</td>
</tr>
<tr>
<td><strong>Mean</strong></td>
<td>0.87</td>
<td>0.15</td>
<td>0.13</td>
<td>0.47</td>
</tr>
</tbody>
</table>

One can observe from Table 3 that...

- Human resources tend to be highest in pediatric centres;
- Nursing resources tend to be lowest in adult centres;
- Physiotherapy and psychosocial resources tend to be lowest in adult centres and in the smallest combined pediatric/adult centres;
- Beyond the above three observations, there is wide variation in human resource/patient ratios in all core disciplines from centre to centre with no consistent or clear explanation or justification.

*See tables 5 to 9 in Annex 5 for a breakdown by Centre.*

**Optimal levels**

The assessors gathered views from all Program staff on the recommended staffing levels to optimally respect Standards of Care and also considered comments made through the patient satisfaction survey. The numbers in brackets represent the additional staffing in FTEs that is recommended.

Table 4: IBDCCC current FTEs and recommended additional staffing

<table>
<thead>
<tr>
<th>Centre</th>
<th>Hemophilia A and B patients</th>
<th>Nursing</th>
<th>Physiotherapy</th>
<th>Social work</th>
<th>Admin/data</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Pediatric</td>
<td>1.6 NP</td>
<td>0.4</td>
<td>0.3</td>
<td>0 (1.0)</td>
</tr>
<tr>
<td>2</td>
<td>Pediatric</td>
<td>0.6 (1.0)</td>
<td>0.15 (0.3-0.4)</td>
<td>0.2</td>
<td>0.35</td>
</tr>
<tr>
<td>3</td>
<td>Pediatric</td>
<td>1.6 (2.0)</td>
<td>0.5 (1.0)</td>
<td>0.33 (1.0)</td>
<td>0.25 (1.0)</td>
</tr>
<tr>
<td>4</td>
<td>Pediatric</td>
<td>0.5 (0.7)</td>
<td>0.05 (0.2)</td>
<td>0.1 (0.2)</td>
<td>0.2 (0.4)</td>
</tr>
<tr>
<td>5</td>
<td>Pediatric</td>
<td>0.9 (1.1)</td>
<td>0.2 (0.4)</td>
<td>0.2 (0.3)</td>
<td>0.2 (0.5)</td>
</tr>
<tr>
<td>6</td>
<td>Adult</td>
<td>1.3 (2.0)</td>
<td>0.4 (0.8)</td>
<td>0.4 (0.8)</td>
<td>0.5 (1.5)</td>
</tr>
<tr>
<td>7</td>
<td>Adult</td>
<td>1.0* (1.6)</td>
<td>0.2 (0.4)</td>
<td>0.2 (0.4)</td>
<td>1.0 (1.5)</td>
</tr>
<tr>
<td>8</td>
<td>Adult</td>
<td>1.5 (2.0)</td>
<td>0.4 (0.6)</td>
<td>0.1 (0.2)</td>
<td>0.8 (1.0)</td>
</tr>
<tr>
<td>9</td>
<td>Adult</td>
<td>1.0</td>
<td>0 (0.2)</td>
<td>0 (0.2)</td>
<td>0.4</td>
</tr>
<tr>
<td>10</td>
<td>Adult</td>
<td>0.7 (1.0)</td>
<td>0 (0.2)</td>
<td>0.1 (0.2)</td>
<td>0.1 (0.2)</td>
</tr>
<tr>
<td>11</td>
<td>Ped./adult</td>
<td>1.5** (2.0)</td>
<td>0.3 (0.4)</td>
<td>0.4 (0.8)</td>
<td>1.0 (1.5)</td>
</tr>
<tr>
<td>12</td>
<td>Ped./adult</td>
<td>1.2</td>
<td>0.6 (1.0)</td>
<td>0.1</td>
<td>1.5</td>
</tr>
<tr>
<td>13</td>
<td>Ped./adult</td>
<td>0.5 (1.0)</td>
<td>0.1 (0.2)</td>
<td>0.2 (0.4)</td>
<td>0.5 (1.0)</td>
</tr>
<tr>
<td>14</td>
<td>Ped./adult</td>
<td>0.8</td>
<td>0.2</td>
<td>0.2</td>
<td>1.0</td>
</tr>
<tr>
<td>15</td>
<td>Ped./adult</td>
<td>2.3</td>
<td>0.4</td>
<td>0.2 (0.3)</td>
<td>0.6 (1.0)</td>
</tr>
<tr>
<td>Centre</td>
<td>Hemophilia A and B patients</td>
<td>Nursing</td>
<td>Physiotherapy</td>
<td>Social work</td>
<td>Admin/data</td>
</tr>
<tr>
<td>--------</td>
<td>-----------------------------</td>
<td>---------</td>
<td>---------------</td>
<td>-------------</td>
<td>------------</td>
</tr>
<tr>
<td>16 Ped./adult</td>
<td>179</td>
<td>1.0</td>
<td>0.2</td>
<td>0.1</td>
<td>0.02 (0.5)</td>
</tr>
<tr>
<td>17 Ped./adult</td>
<td>104</td>
<td>1.0</td>
<td>0.1</td>
<td>On call (0.2)</td>
<td>0.6</td>
</tr>
<tr>
<td>18 Ped./adult</td>
<td>40</td>
<td>0.5 (1.0)</td>
<td>0 (0.2)</td>
<td>0 (0.2)</td>
<td>0.25</td>
</tr>
<tr>
<td>19 Ped./adult</td>
<td>139</td>
<td>2.0</td>
<td>0.5</td>
<td>0.6</td>
<td>2.5</td>
</tr>
<tr>
<td>20 Ped./adult</td>
<td>62</td>
<td>0.6</td>
<td>0.025 d/y (0.2)</td>
<td>0(0.1)</td>
<td>0 (0.2)</td>
</tr>
<tr>
<td>21 Ped./adult</td>
<td>211</td>
<td>1.4</td>
<td>0.2</td>
<td>0 (0.2)</td>
<td>1.0 (1.5)</td>
</tr>
<tr>
<td>22 Ped./adult</td>
<td>396</td>
<td>4.0</td>
<td>1.0</td>
<td>0.1 (0.5)</td>
<td>1.0</td>
</tr>
<tr>
<td>23 Ped./adult</td>
<td>134</td>
<td>1.5 (2.0)</td>
<td>0.1 (0.2)</td>
<td>0.1 (0.2)</td>
<td>0 (1.0)</td>
</tr>
<tr>
<td>24 Ped./adult</td>
<td>89</td>
<td>0.2 (0.5)</td>
<td>0.008 (0.1)</td>
<td>0.008 (0.1)</td>
<td>0.1</td>
</tr>
<tr>
<td>25 Ped./adult</td>
<td>56</td>
<td>0.2</td>
<td>0.008 (0.2)</td>
<td>0 (0.1)</td>
<td>0.2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>3,785</strong></td>
<td><strong>28.4 (5.6)</strong></td>
<td><strong>5.9 (3.7)</strong></td>
<td><strong>3.9 (4.1)</strong></td>
<td><strong>14.0 (7.7)</strong></td>
</tr>
</tbody>
</table>

NP – Nurse Practitioner*
1.6 for all blood/immune disorders**
2.5 for all blood/immune disorders

4. **Staff recommendations to sustain/improve optimal care to meet the Standards**

The principal recommendations are:

**Human resources**
- Increase the FTEs in nursing, physiotherapy and/or psychosocial support where currently needed and evaluate as the Programs grow; (23)
- Increase funding for administrative support and data entry so as to have the capacity to enter data into CHARMS in a timely way in support of patient care and health outcome research; (10)
- Allocate dedicated physiotherapy and social work time to the Program; (9)
- Add a psychologist to the core team; (2)
- Increase time for the hematologist; (2)
- Identify and assign to the Program an oral surgeon with interest in treating people with bleeding disorders; (2)
- Increase access to pain management specialist; (2)
- Identify and assign to the Program an OB-GYN with interest in treating girls and women with bleeding disorders. (1)

**Services**
- Increase number and/or time of clinics; (9)
- Increase involvement in clinical research; (3)
- Increase capacity to do PK testing and use data; (2)
- Improve the formal transition program from pediatric to adult care; (2)
- Expand outreach clinics; (1)
- Create an effective on-call system; (1)
- Improve clotting factor concentrate distribution and utilization; (1)
- Hold regular clinics for girls and women with bleeding disorders; (1)
- Increase use of Telemedicine; (1)
- Increase education of patients on bleed recognition. (1)

Physical and information resources
- Create an improved electronic patient reporting system (e.g. a SmartPhone app) and a renewed commitment by patients/families to accurately report utilization; (8)
- Build more capacity in the coagulation lab; (5)
- Develop formal written policies and procedures to promote quality care; (4)
- Have dedicated clinic space; (2)
- Buy Smartphones for the Centre; (2)
- Obtain appropriate physiotherapy equipment for the exam rooms; (1)
- Create a web-based educational tool for teens to improve adherence to prophylaxis schedules and infusion reporting. (1)

Training, Continuing Education
- Support Continuing Education for all core team members; (9)
- Create a mentorship program in physiotherapy to support training and continued education. (1)

Relationships, Outreach
- Make the Program more visible within the hospital and with health authorities; (5)
- Continue and, where warranted, expand travelling clinics. Where patients live in remote communities, the Ministry of Health should provide travel assistance to allow them to attend annual or semi-annual clinic assessments; (2)
- Create more awareness by administrators of the health care and financial benefits of home infusion programs by administration; (1)
- Do more training in Emergency Departments; (1)
- Do more education by the CHS and its chapters on infusion. (1)

Organizational
- Require by government mandate (following the lead of Quebec and Manitoba) that all patients who use clotting factor concentrates be registered in a IBDCCC. Accompany this expanded mandate with sufficient resources to carry it out; (6)
- Mandate a bar code system for clotting factor infusion reporting, which allows scanning both by patients in the home and by health care providers, linked to a national registry. (2)

Funding
- Provide Ministry recognition of Programs with envelope funding; (4)
- Provide more financial assistance from chapters to families in need to attend clinic (gas, parking, food) and summer camp, and for specialized equipment such as helmets and mobility aids. (4)
Section E: Key observations by patients

A random selection of 3000 patients who had been seen in clinic in the last two years was made using the Canadian Hemophilia Registry (CHR) database. Patient satisfaction surveys were sent by mail by 20 of the 25 Canadian centres in the first half of 2014. Due to problems with CHR identifiers and varying degrees of participation by hemophilia / inherited bleeding disorder programs, it is not possible to state with any accuracy the number of questionnaires actually distributed; however, 347 were completed and returned to the Canadian Hemophilia Society for compilation. Responses were anonymous. Not all questions applied to each respondent.

This summary presents the quantitative results, some comments from the assessors and patient quotes to illustrate particular issues. The full results of the survey are available in Annex 2.

1. 96% (237/248) are satisfied with the availability of the centre team when needing to be seen for an urgent problem.

   Sixteen people indicated that they live between 1 to 9 hours away from the Centre, which prevents them from going to the clinic without an appointment for an urgent need or a new problem. Some indicated that they therefore tend to rely more on phone and email communications or they visit their local Emergency Department. Among these, many indicated being satisfied with the phone support. In one case, they were directed to a local hospital with which the HTC was in touch and in another the nurse coordinator arranged the necessary treatment in preparation for when the patient was to arrive at the HTC.

2. 96% (230/240) are satisfied with the care they receive when needing to be seen for an urgent problem.

   Nineteen people commented being very satisfied with the care and attention they receive at the Centre.

   I phoned (really out of the blue) because I had a previously diagnosed blood disorder, needed dental surgery (which was not going to be done until I went to the blood clinic). I was seen immediately AND compassionately.

3. 88% (302/342) are supplied with a FactorFirst wallet card to facilitate care at the Emergency Department.

   A wallet card with bleeding disorder info for a triage/emergency nurse/doctor would help especially for 1) unsuccessful home infusion 2) urgent/ new medical problem.

4. 62% (167/271) reported the medical information on the card is updated annually.

   Nine people indicated the FactorFirst gets updated every two years and, for many, during their appointments set every other year. Eight people indicated it is updated as needed if their conditions change.

5. 96% (152/158) are satisfied with the arrangements that are in place for home treatment (for example, telephone access to nurse coordinator, education in home infusion techniques, supply of factor concentrates, supply of infusion equipment).

   Nine people commented being very satisfied and have found the system efficient; however, some patient concerns were raised.
We are required annually to do a one-on-one clinic with our nurse to ensure we are doing techniques correctly and sterilizing correctly.

Our nurse coordinator is impossible to reach, I always get her voicemail and can go days without a call back only to find out she's on holiday, sick or just days off. Our clinic really needs a full-time nurse coordinator.

We have to purchase the infusion equipment and we have no medical coverage. It's very expensive because our son has a port. 12 needles are $200.

6. 59% (141/240) on home infusion regularly fill out an electronic or paper diary about home treatment/bleeding events; 5% (7/148) do not fill out a diary even though they are asked; 20% (38/240) report they are not asked to fill out a diary about home treatment/bleeding events.

I always fill out the diary (maybe not always in a timely manner;) way easier with the online services now.

I've never been asked for it, so found it to be a needless waste of my time, so I stopped.

There is no follow through and it is very old school (paper). Very inefficient, would prefer electronic process online.

Would be nice if our clinic used EZ log or any digital log.

Usually phone in to data clerk at HTC for record of bleed.

I don't think the comprehensive care centre is reviewing these records. There is no contact from clinic during periods of high usage to cope with serious bleeds or trauma.

7. 18% (60/339) report they visited their centre for a scheduled check-up every 6 months; 49% (167/339) report they visited their centre for a scheduled check-up every 12 months; 14% (49/339) report they visited their centre for a scheduled check-up every 24 months; 5% (16/339) report they never visited their centre for a scheduled check-up; 14% (47/339) report they visited their centre on a different schedule.

Should be once a year but it is always very difficult to get an appointment. I think I have waited up to 3 years.

We are invited to attend the Wednesday clinics but opt not to because of our distance.

Tough to get to from our town to Vancouver, especially when clinic days are Tuesdays.

The team has been to my hometown hospital a few times for clinics and I have seen them when they were here. I live 5 hrs away from the clinic and I have only attended a clinic a few times except when I was hospitalized in St John’s.

Usually done by Telemedicine from my community to HTC.

8. 95% (318/334) report they meet their physicians at the time of their regular check-up; 96% (321/334) report they meet their nurses at the time of their regular check-up;
52% (173/334) report they meet their physiotherapists at the time of their regular check-up; 33% (112/334) report they meet their social workers at the time of their regular check-up.

Other specialties mentioned in comments: dentist (17); rheumatologist (9); orthopedic surgeon (5); genetics counselor (5); surgeon (5); medical student/resident (5); administrative assistant-secretary-receptionist (5); research nurse (4); ob-gyn (3); lab personnel related to blood work (3); pediatrician (2); psychiatrist (1) nutritionist (1); gastroenterologist (1).

*We spend more time waiting in between members than actually with them so feel this too is a waste of time.*

*The social worker presently at the clinic has indicated a lack of understanding of hemophilia. Several years ago, she pointed to judo and other martial arts as a good form of exercise!*

*My physiotherapist is awesome.*

*Very often other team members (i.e. social work, physiotherapist) are not available.*

9. 92% (301/326) are satisfied with the arrangements in place for regular check-ups.

Fifteen people indicated wait times are too long.

*We are also happy that they are now willing to offer an outreach clinic in our community once a year.*

*Infrequent appointment times: "We have an opening 6 months from now or 9 months from now."*

10. 98% (317/325) report all their questions are answered to their satisfaction at regular check-ups.

11. 93% (171/183) report they are satisfied with the physiotherapy and orthopedic services that are available for the management of joint problems.

Five people, surprisingly, indicated not being aware this service existed.

*Physio services have been available for about a year. My physiotherapist is great, very knowledgeable and professional.*

*Having a physio available has made a great difference in preventing joint bleeds.*

*The physio does not appear to receive much training regarding joint health and bleeding disorders.*

*A friend and four other people had their surgery canceled twice because of lack of nurses to administer product after surgery, which I found disheartening.*

12. 21% (73/343) report that dental services are offered through their clinic; 28% (95/343) report that dental services are not offered through their clinic; 51% (175/343) report they do not know if dental services are offered through their clinic.

*Eleven people indicated not being sure if this service was offered.*

*My son has had dental services arranged in the past for problems with his teeth/gums. This service was provided in conjunction with the nurse coordinator and it was excellent.*
It would be a great benefit since dental procedures are a big issue, despite regular cleaning and check-ups several times a year.

Most times we see a dentist at a clinic visit but we do have our own family dentist and always consult with the bleeding disorders clinic before any procedures are performed.

13. 78% (46/60) report they are satisfied with the dental services offered through the Program.

We had to make the appointment and coordinate with clinic for treatment; there were no issues.

14. 50% (56/112) report that the cost of dental services is covered.

15. 55% (149/272) report they have access to a social worker if needed; 5% (13/272) report they do not have access to a social worker if needed; 40% (110/272) report they do not know if they have access to a social worker if needed.

The children’s clinic has not been able to maintain a social worker, but the social worker at the adult clinic was available and more than happy to help and VERY knowledgeable.

Excellent. Our child has been bullied due to his bleeding disorder and she helps him cope.

Would be great to have regular phone ‘visits’ with new parents to see how they are doing. Don’t wait for the parent to call the SW; make a weekly (?) call simply part of the program to keep lines of communication open. Can lower number of calls as parents become more comfortable with their new BD child. Great way to lower stress and allow gradual supported learning.

16. 27% (73/267) report they have access to a psychologist if needed; 7% (21/267) report they do not have access to a psychologist if needed; 65% (173/267) report they do not know if they have access to a psychologist if needed.

I think a psychologist would be an asset as my son has had resentment and feelings I was unsure how to handle with regards to frequent infusions.

The HTC appears unable to retain psychologists; they are like trying to see God or Jesus Christ in the flesh.

17. 85% (68/80) report they are satisfied with the psychosocial services offered through the Program.

We chat briefly with a social worker but that’s not long term counseling, which would be beneficial if offered.

18. 91% (39/43) report that they were satisfied with how the clinic recently helped with transition from pediatric to adult care.

I started with the clinic at 16 and I am now 19. I didn't notice any changes if there were any.

My oldest son graduated to adult care and he found the adult clinic to be not nearly as accessible.
19. 78% (238/307) report the clinic team provides information and advice to other health care providers (for example, pediatricians, family physicians, dentists, etc.) who care for the them or their children; 5% (16/307) report the clinic team does not provide this information and advice; 17% (53/307) report they do not know if the clinic team provides this information and advice.

They always communicate with our local doctor and send him updates after our yearly appointments.

They have been amazing at this and have made a real difference to my care.

Team sent note to my family doctor and cardiologist (needed his input re DDAVP). They are available if dentist or other ER, etc. need advice. Have prescription and instruction for upcoming dental work.

Clinic provides my physician with all information/results of annual check-up.

This is something that needs to be done better. The GPs don't understand and aren't communicated with.

This should be done in all situations. Not all other care providers are necessarily and sufficiently informed about hemophilia issues.

Reports sent to family doctor. Excellent when travelling, providing factor and notifying me and the area that I am visiting in case of emergency.

The doctors actually did a seminar for the dentists in our area to educate them on bleeding disorders.

20. 58% (131/226) report the clinic team provides information and advice to people in their community (for example, teachers, daycare workers, employers) if requested; 6% (14/226) report the clinic team does not provide this information and advice; 36% (81/226) report they do not know if the clinic team provides this information and advice if requested.

The nurse came to our daycare and talked to the supervisor.

They regularly offer to provide information, advice or visits to our sons' teachers.

I asked my son's nurse to do a presentation as he starts kindergarten in September but she is not able to.

They have given school presentations, calls, etc. Fantastic support.

21. 82% (256/311) are satisfied with access to the centre, for example: parking, after-hours entrance, signage, availability of wheelchairs in the building; 18% (55/311) are not satisfied.

Twenty-five people indicated parking as very costly. Nineteen commented that access to the Centre itself is problematic and directions non-existent.

The clinic is quite difficult to find and information services were not helpful and did not know that the clinic existed. Parking is too expensive. This could really impact a family that needed to visit frequently.

Parking increases the stress of the situation; can the CHS fund a parking program?

Shuttle service should be provided from parking lot to hospital.
22. 91% (203/222) report it is easy to book an appointment if they or their children need to go to the centre for help between regularly scheduled appointments for a non-urgent medical reason.

The clinic team always makes accommodations to get us in for an appointment.

Not always. Particular staff seem to be away different days of week. It may help if everyone had a regular schedule.

If I call the clinic, they are always available to talk to me or will call me back in a timely fashion.

I had difficulty booking appointment, not clear who to call.

23. 23% (40/171) report they are seen immediately; 40% (68/171) report they are seen the same day; 10% (17/171) report they are seen the next day; 27% (46/171) report they are seen 2 or 3 days later.

Every time I have requested a visit it has always been on the day I requested.

4 to 6 weeks. I have had a hard time convincing the clinic nurse that I need to be seen.

Very accommodating to me! Nurse is amazing and tireless!

However, I have a concern about the after-hours on-call phone service being eliminated. This is valuable. In the past, I have had ER treatment given using the wrong protocol (i.e. intravenous instead of subcutaneous). This resulted in a shock response driving home. The on-call nurse had not been consulted by ER. If the on call service were eliminated, the potential for these incidents would only increase.

It depends on the issue and who I’m willing to see about it. My regular nurse only works part-time and I’d rather wait to see her than explain my whole history to someone for a simple question.

24. 86% (273/316) report they know whom to contact for help if the comprehensive care clinic is closed or after hours.

25. 70% (166/236) report they are satisfied with the care they have received at the Emergency Department.

Thirty-nine people indicated that the main issue is that Emergency personnel, especially in those hospitals that do not house an IBDCCC, lack knowledge about bleeding disorders.

We don’t visit the ER anymore now that we do home infusions, but it was very frustrating and time consuming at our local hospital. Always had to be admitted and send to PEDS instead of treated in ER.

We get very good (although maybe not as knowledgeable) service in emerg. There, we are people and not an inconvenience. The docs are great (know hemophilia) but the nurses don’t always. As a parent, I have to make sure I know the treatment plan because the clinic doesn’t communicate quickly with emerg.

Not always, they often do not believe you have a bleeding disorder even if you show your card.

Had a joint bleed and waited 4 hours before getting factor (now we self-infuse).
Emergency departments do not seem to be helpful to people with bleeding disorders. They do not seem to believe the patient or know what to do.

They don't understand and have tried to kill me a few times doing things they shouldn't.

I consider myself to be very well educated on the subject and find ER visits to be a very frustrating experience. Last time we saw SIX doctors before he was given his factor and two of them told me to give him ibuprofen.

Local ER doctors and medical staff have very limited hemophilia knowledge. I know more than they, and have them contact my clinical team for advice.

We have had some good and some horrible experiences. However, the nurses at our clinic are very efficient with contacting ER to check on our visits and complaints.

I feel that rural hospitals do not have enough information regarding bleeding disorders or the implications of a severe joint injury ... and because of that I will transport my child to Saskatoon when the need arises.

The emergency department at the local hospital does not provide proper care.

Not always: most doctors have little knowledge of hemophilia and when to give the factor needed.

26. What do you think is very good about your comprehensive care clinic?

The vast majority, 89 of the respondents who commented, indicated that it is the staff team that makes their Centre very good. Most indicated that they find them to be very caring, kind, knowledgeable, personable, understanding, sensitive, empathetic, reassuring, friendly, courteous, helpful and committed. Continuity and minimal turnover of staff were also mentioned as positive elements.

The quality of the care and treatment was also rated very highly by a vast majority underlining efficiency, competency, compassion, dedication and professionalism. Services were said to be well organized and meticulous. Many feel they have established trusting, strong, long-term relationships with their Program team members particularly with the nurse coordinators. They feel they are treated with respect.

Many respondents find the Program staff very accessible, accommodating, attentive, thorough, informative and centered on their needs both as a patient but also as a human being. Many said the Centres have a family feeling.

Having a multi-disciplinary team that has wide and varied expertise was also deemed to be very valuable. This gives better access to specialized physicians, and reduces wait time for appointments. They work together at troubleshooting problems and finding solutions.

Regarding communications, respondents indicated they appreciate the open communications, being listened to and the ease with which they can communicate with the members of their Program team. Being very accessible by phone and email when needed and providing answers to questions quickly are also much appreciated, as well as follow-ups and the occasional unsolicited phone check-up to find out how they are doing. Knowing they can reach someone 24/7 is also much appreciated.

Regarding the Centre itself, many stated that having a comprehensive care centre for bleeding disorders with the specialized programs and services offered all in one
location, including good coagulation labs, is a major asset. The coordination by medical personnel to meet all specialties in one appointment instead of having to return several times for separate visits is valued. Having a Centre in the city where they live or which is close by is also appreciated. Travelling clinics that provide service at a distance from the main Centre are also highly appreciated. People feel they can be seen quickly and efficiently. An IBDCC provides access to most medical specialties. The information Program staff provide to other health care service professionals and the coordination of care beyond the Centre itself are seen as very valuable. The patient and their family members are well guided regarding the treatment and care of bleeding disorders.

The fact that factor concentrates are available 24/7 or can be sent quickly and good ordering / pick-up services are all highly appreciated. Up-to-date medical information and educational services are valued by many as well as the research activities that are conducted. Being able to be access services in English and French was also identified as important.

See Annex 2 for all comments.

27. What do you think is most in need of improvement at your comprehensive care clinic?

Fifty-eight (58) people indicated nothing needed to be improved or that they were very satisfied with everything.

Seventeen (17) people indicated more personnel, including nurses, physiotherapists, physicians, social workers and psychologists, are needed. Of note, a few mentioned the need for greater access to nurse practitioners.

Sixteen (16) people identified long wait times as an issue and suggested that scheduling of appointments needs to be improved to make better use of time both for the clinic staff and for the patients. People request less wait time between meetings with clinic members. More flexibility with appointment dates and times was also suggested. It was requested that health care providers be punctual and stick to schedules.

Fifteen (15) people raised issues about the physical resources such as the need for more beds/rooms, a more permanent location for the clinic, and larger and more adequate work spaces, including better waiting rooms. More and better up-to-date equipment and waiting rooms with toys and other things to keep the children busy and amused were mentioned. One person mentioned that the signage needs to be improved as the Centre is hard to find.

Thirteen (13) people indicated parking as an area needing improvement. Some suggested instituting a special rate for patients and also having the CHS chapters help out patients with a special parking subsidy program.

Ten (10) people indicated issues related to the fact that they live far from the clinic which involves long travel times and expenses. Some would like to see clinics closer to home or more outreach clinic activities/services and better training for their local Emergency Departments.

Four (4) people indicated that weekend and after hours coverage should be in place.

See Annex 2 for all comments.
28. 4% (13/341) report having ever made a complaint.

29. 27% (3/11) report the complaint process was made clear to them.

30. 62% (5/8) report the complaints were handled to their satisfaction.
Section F: Canadian Hemophilia Society observations and recommendations

This section presents a summary of the observations and recommendations included in the individual centre assessments.

Human resources
Despite dedicated and well-trained staff, 23 of the 25 Programs lack human resources in one or more of the following core disciplines: hematology, nursing, physiotherapy, social work and clerical/data entry (key indicator 1-2). In nine of the 25 Programs, no resources are allocated to certain core disciplines, notably physiotherapy and social work. The level of resources varies widely and inexplicably from Program to Program: from 0.2 to 1.5 Full Time Equivalents (FTEs) per 100 hemophilia A and B patients in nursing; from 0 to 0.4 FTEs per 100 patients in physiotherapy and social work, and 0 to 1.8 FTEs in clerical/data entry. The centre assessment revealed that 52.2 FTEs are currently funded in the core disciplines of nursing, physiotherapy, social work and clerical/data entry across Canada. An additional 21.1 FTEs are considered necessary to help Program staff meet the current challenges of increasing numbers and respect Standards of Care. At an average of $70,000 per FTE, this represents a national investment of less than $1,500,000, or approximately one-half of one percent (0.5%) of the current total budget of $270,000,000 for the care of people with inherited bleeding disorders.

Many Programs are subject to increasing hospital, regional health authority or Ministry of Health pressure to limit or even reduce existing resources, despite a 75% increase in the number of patients registered in the 25 Programs in the period 2004-2014 and increasing demands on services. Only a few provinces have given provincial designation to their Programs for these rare inherited bleeding disorders (disease incidence of 1 in 10,000 to 1 in 1,000,000) requiring specialized and expert care. Budget restrictions at the Program level are viewed by the CHS as “penny-wise.”

Recommendation 1: That health officials in the provinces and territories consider the results of the individual Centre assessment reports and adjust human and physical resources in IBDCCCs so that Standards of Care can be respected and optimal care provided. Of paramount importance are the core team disciplines: physiotherapy, social work, administration/data entry, pediatric and adult physician, nursing.

A number of Programs indicated a lack of availability of extended team members, as prescribed in the Standards of Care (key indicator 1-7a). Specific disciplines identified include dentistry, obstetrics-gynaecology, rheumatology, orthopedics and pain management.

Recommendation 2: That Centre Directors strive to establish effective relationships with extended team members (where they do not already exist) so that care can be truly comprehensive. Where Centres are small or where expertise is unavailable, a referral network should be established with experts in neighbouring Programs.

Data collection
Hemophilia care is changing quickly with the advent of a new generation of factor concentrates that will require long-term research to measure their impact on health outcomes. Provincial and territorial governments are requiring increased monitoring of the utilization of blood products and their recombinant alternatives. Sufficient human resources for data collection and entry are critical. Research and involvement in national databases are
identified as two of the 11 responsibilities of a HTC in the Standards document (key indicators 1-8a, 1-8b, 1-8c, 2-2b). Twenty-one of the Programs reported issues with the collection and analysis of patient data as a key barrier to optimal health care delivery.

To facilitate infusion reporting, data collection and health outcome research, the Association of Hemophilia Clinic Directors of Canada and McMaster University are developing the Canadian Bleeding Disorder Registry (CBDR) to replace the outdated Canadian Hemophilia Assessment and Resource Management System (CHARMS). This new integrated information system will be implemented at Canadian IBDCCCs starting in 2015, which will result in improved data collection for individual patient care, clinical research and utilization monitoring. This information system has the potential to significantly improve home infusion reporting, data collection and health monitoring by Centre staff, and health outcome research across the country and even internationally. It will attain these goals, however, only if the CBDR is adequately funded in the medium to long term. The cost is estimated at $300,000-$400,000 per year to house, maintain and develop the registry, and an additional $300,000 per year for badly needed data entry resources in the Centres. This represents approximately one-quarter of one percent of the cost of coagulation therapies.

**Recommendation 3:** That the provinces and territories support the medium and long-term operational costs of the Canadian Bleeding Disorder Registry so that utilization of coagulation therapies can be effectively monitored, individual patient care improved and overall health outcomes evaluated.

**Recommendation 4:** That hospitals, regional health authorities and Ministries of Health (as appropriate) provide sufficient resources in data entry/management so that the Canadian Bleeding Disorder registry can be used to its full potential.

**Clinics and outpatient services**

Because of lack of clinic time or space, nine of the 25 Programs are unable to respect the schedule for regular health assessments as prescribed in the Standards of Care. In at least six Centres, clinic space is inadequate to allow patients to be seen by the multi-disciplinary teams that make up comprehensive care centres. It is critical that patients are able to access the full comprehensive care team both during regularly scheduled appointments and during walk-in visits for acute bleeding problems (key indicators 3-2a, 3-3). Several centres are unable to set aside time and space for dedicated clinics for girls and women with inherited bleeding disorders (key indicator 3-2a). Both health care providers and patients expressed a strong appreciation for travelling clinics.

**Recommendation 5:** That hospitals ensure that there is adequate time and space for interdisciplinary clinics so that patients can be assessed as per the schedules defined in the Standards of Care.

**Recommendation 6:** That travelling clinics be continued and, where numbers warrant, expanded.

**Recommendation 7:** That where patients live in remote communities, the provincial governments provide travel assistance to allow them to attend annual or semi-annual clinic assessments.
Physical resources

New techniques in point of care ultrasound imaging to evaluate specific aspects of acute and chronic joint health are being introduced in some Canadian IBDCCCs. As this bedside equipment becomes incorporated into joint health assessment, personnel need to be trained and skills maintained to facilitate its use (key indicator 3-1). Used appropriately, this technology has the potential to identify bleeds that require treatment and avoid treatment when no bleed is occurring, as well as monitor long-term joint health and facilitate educational discussions between the team and patient at the bedside. Eleven of the Programs expressed a keen interest in adopting this technology.

Recommendation 8: That ultrasound diagnostic imaging be introduced at the bedside in Canadian IBDCCCs as this equipment becomes accepted as standard of care, and personnel be trained in its use.

Several Programs have started to use SmartPhones to take advantage of increasingly popular ways of communicating, including texting. This can decrease appointment no-shows, and increase adherence to treatment protocols and factor concentrate utilization reporting.

Recommendation 9: That Programs be provided with Smartphones to take advantage of modern ways of communicating, and that privacy regulations be developed in hospitals/health authorities to facilitate this style of communication.

Policy

The very success of the Programs—a home care model of treatment for even the most severely affected patients—results in a low number of in-person visits to the Centres and to the Emergency Departments, and hence lower visibility. The role of the teams in providing support to patients and remote health care providers needs to be recognized and supported (Scope of Care Standard 3, key indicator 1-3c). In many cases, directions to the Centres need to be improved, both on site and on the hospital websites.

Recommendation 10: That Programs make efforts to be more visible to hospital administrations, Ministries of Health, outside agencies and patients.

Inherited Bleeding Disorder Comprehensive Care Programs serve patients across large geographies and multiple health regions. Some individual Programs serve entire provinces. Dedicated provincial funding from Ministries of Health, similar in design to that of the Saskatchewan Bleeding Disorders Program, should be provided to Programs.

Recommendation 11: That Inherited Bleeding Disorder Comprehensive Care Programs be recognized by Ministries of Health as having provincial mandates and that provincial or designated envelope funding be provided (where this is not already the case).

Recommendation 12: That Provincial Inherited Bleeding Disorder Councils, made up of health officials, representatives from the province’s IBDCCCs and the patient organization, be created to advise the Ministry of Health.

Coagulation therapies

The cost of coagulation therapies (factors I, II, VII, VIII, IX, XI, XIII, VIII/VWF and factor VIII bypassing therapies) in 2013-14 was $204,000,000 for Canadian Blood Services and $46,000,000 for Héma-Québec for a total of $250,000,000, despite a significant decrease in the per unit cost of recombinant factor VIII—factor VIII represents close to 50% of the total
coagulon product budget —compared to previous years. Prescription of these biological products requires the expertise of hematologists experienced in the care of people with inherited bleeding disorders, expertise and experience that resides only in physicians working in IBDCCCs. Approximately 90% of these products are infused by patients or their caregivers via home infusion programs to prevent bleeding, a Standard of Care for many patients in Canada and around the world for the last several decades. Many Programs, however, describe a lack of capacity to adequately monitor the optimal utilization of these clotting factor concentrates used in home infusion protocols and their key clinical outcomes. Systems to report home infusions in accurate and timely ways are inadequate. Nurses are unable to respond quickly to critical care issues as identified by accurate and timely reporting of factor utilization. Under- and over-utilization occur. Sub-optimal health outcomes, including unnecessary bleeding and joint damage, are the results. Product wastage occurs in such an environment.

The cost of coagulation therapies, therefore, represents 90 to 95 percent of the total costs for the care of people with bleeding disorders. A silo approach to funding the care of people with inherited bleeding disorders is a barrier to rational resource allocation; hospitals are unaware of and perhaps unconcerned with the cost of factor concentrates reimbursed via the provincial blood budgets, and Ministries of Health have little control over hospitals’ human resources. The CHS views the current under-funding of Programs, whose role is to facilitate the best health outcomes with such valuable coagulation therapies, as “pound-foolish.”

Why is this a critical time to correct the problems?

A key indicator of the level of hemophilia care in a country is the number of International Units (IUs) of factor VIII consumed per capita. Canada currently uses 5.7 IUs per capita, 25-50% less factor VIII than developed countries such as United States, United Kingdom, Australia, Ireland and Sweden, in part due to historically conservative prophylactic protocols. In Canada over the last five years, utilization of factor VIII has been increasing at a rate of 6% per year. The recent 40-50% decrease in the per unit cost of factor VIII in Canada is very likely to be accompanied by an increase in utilization, as patients and physicians adopt prophylactic regimens that more effectively protect against bleeding and improve quality of life. At the same time, extended half-life factor VIII and IX concentrates, the first advance in the efficacy of factor therapies in four decades, are being introduced. The abilities to document utilization and evaluate health outcomes as clinical practices evolve are more critical than ever. This can only be done with adequate human resources in the Centres.

It is current practice in some provinces that clotting factor concentrates are made available by prescription only to patients who are registered in a Hemophilia Program (key indicator 1-4). In this way, physicians prescribing concentrates and treating patients outside the Centre can be put in touch with the Program specialists and benefit from the Centre’s high level of knowledge and experience. Product utilization is optimized.

**Recommendation 13:** That IBDCCCs be given a provincial mandate for the prescription of clotting factor concentrates such that, except in emergency, they can only be prescribed to patients registered in a Program; and that outlying hospitals that distribute clotting factor concentrates be required to report distribution to the Program (where this is not already the case).

More education is needed regarding accurate and timely home infusion reporting, which represents approximately 90% of clotting factor concentrate usage. With the launch of the Canadian Bleeding Disorder Registry in 2015, the timing is ideal for such an initiative.
Recommendation 14: That the Canadian Hemophilia Society and the Canadian Association of Nurses in Hemophilia Care develop education and awareness tools to improve home infusion reporting.

Tranexamic acid and desmopressin are key drug therapies used in the treatment of inherited bleeding disorders and should be included in all provincial drug formularies. Where not available because of cost barriers, patients may turn to expensive clotting factor concentrates, which are provided at no cost through the blood budget. Increased access would improve patient care and conserve valuable clotting factor concentrates.

Recommendation 15: Add tranexamic acid and desmopressin to provincial drug formularies (where this is not already the case) and remove any funding barriers to patients who require these drugs.

Continuing education

It is critical that all core team members be able to benefit from attendance at the annual national meetings of their associations. Hemophilia and bleeding disorders are rare conditions; continuing education is feasible only through quality interactions with peers across Canada (key indicators 1-15a, 1-15b). This training should be supported and facilitated by hospitals. Thirteen of the 25 Programs indicated there are barriers to core team members accessing continuing education opportunities.

N.B. The cost of attending annual meetings of health care provider associations is borne by the Canadian Hemophilia Society.

Recommendation 16: That IBDCCCs and the hospitals that house them support professional training and continuing education for core team members for these rare conditions through their national associations, namely: Canadian Association of Nurses in Hemophilia Care, Canadian Physiotherapists in Hemophilia Care and Canadian Social Workers in Hemophilia Care.

Research

Hemophilia care is changing quickly with the advent of a new generation of factor concentrates that will require long-term research to measure their impact on health outcomes. Provincial and territorial governments are requiring increased monitoring of the utilization of blood products and their recombinant alternatives. A new integrated information system will be introduced into Canadian IBDCCCs in 2015, which will result in increased data collection, both for clinical research purposes and utilization monitoring. Research and involvement in national databases are identified as two of the 11 responsibilities of an IBDCCC in the Standards document.

Recommendation 17: That hospitals and Ministries of Health recognize that research is a key responsibility of an IBDCCC and, where expertise exists, provide support for clinical research.

Hemostasis lab

While the assessors did not have the capacity to evaluate the quality of services in the hemostasis laboratory, staff in several Centres report that key tests cannot be done in a timely manner. A well functioning hemostasis lab able to perform all basic tests 24/7 and correct diagnoses is critical to a well-functioning Centre (key indicator 1-13a).
Recommendation 18: That Centre directors, laboratory directors and hospital officials review the capacity of the hemostasis laboratory with the goal of being able to perform key tests in a timely manner.

Services
24/7 on-call systems for hematologists and nurse coordinators have proven their worth in providing expert advice on treatment to patients and families, avoiding Emergency Department visits where possible and facilitating timely and appropriate care in Emergency Departments (key indicator 1-6a, b, c).

Recommendation 19: That hospitals support the availability of a 24/7 on-call service using qualified staff.

Patients’ principal criticism of the care they receive is related to the Emergency Department. As care has become more and more home-based over the last three decades, the number of visits to Emergency Departments has decreased and Emergency Department staff have become less accustomed to treating people with inherited bleeding disorders. Patients and caregivers report that care is sometimes sub-optimal and wait times are long, especially in Emergency Departments outside the hospitals that house the Programs (key indicators 1-6c, 3-4a, 3-4b).

Recommendation 20: That hospitals allocate a portion of the nurses’ time to training Emergency Department personnel, including in outlying Emergency Departments, and that this training be mandated.

Telemedicine has the potential to help with remote assessment of acute bleeds and as an alternative to in-person clinic visits for patients at a great distance from the Centre or outreach clinics (key indicators 3-4a, 3-4b).

Recommendation 21: That Centre personnel explore greater use of Telemedicine to overcome barriers to care for people living remotely from Centres.

Summer camps, organized and funded by all ten chapters of the Canadian Hemophilia Society are where most children learn to do self-infusions. They are the ideal places for children to become engaged in and educated about their own care. It is critical Program nurses be present to supervise this learning; unfortunately, in some provinces, nurses must use vacation time to attend camp. Time devoted to learning self-infusion at camp will reduce the time needed for infusion training during busy clinic visits.

Recommendation 22: That hospitals recognize summer camps are fundamental to children with inherited bleeding disorders gaining control over their own health care, and allocate time for IBDCCC nurses to attend and educate children.

Transitioning from a pediatric to an adult care model is a critical time for patients with chronic disease. It is a time when patients with bleeding disorders can abandon preventative care, ignore symptoms of bleeding and experience avoidable complications. While transition is facilitated in those 15 Programs that have common staff and facilities for both pediatric and adult populations, it can be especially challenging when patients “graduate” to new teams in different hospitals.

Recommendation 23: That pediatric and adult comprehensive care teams continue to work together to improve the formal transition programs (key indicator 3-9a). Preparations for transition should begin at the age of 10 or 12.
Some families have financial barriers to accessing optimal care. The provincial chapters of the Canadian Hemophilia Society should work with Program personnel to facilitate providing financial assistance to families in need to attend clinic and summer camp, and for specialized equipment such as helmets and mobility aids.

**Recommendation 24:** That a formal procedure for financial support for families (e.g. mobility aids, funds for travel to clinic and parking) be jointly developed between chapters and comprehensive care teams.

Closer ties and more frequent exchanges between the provincial chapters of the Canadian Hemophilia Society and the IBDCCC care team would be beneficial to discuss and improve services.

**Recommendation 25:** That provincial chapters of the Canadian Hemophilia Society and the IBDCCC care teams should set up formal procedures for regular meetings to discuss and improve services (where this does not already exist).
References

(1) Analysis of the cost of care for inherited bleeding disorders at St. Paul’s Hospital, Vancouver. This analysis included non-labour costs, diagnostic and clinical support services, salaries, office space and the cost of Emergency Department services compared to factor VIII and IX usage over a five-year period. Factor VIII and IX costs alone were found to represent 93% of the total cost of care. The actual percentage of costs related to factor concentrate use is likely to be higher than 93% as bypassing agents (rFVIIa and FEIBA), VWF concentrates and concentrates to treat Factor I, II, VII, XI and XIII were not included in the St. Paul’s costing. Extrapolation of the costs observed at St. Paul’s (an annual average of $805,000 for 432 patients) to the rest of Canada yields an estimated cost of $19,953,000 for the more than 10,000 patients registered.

(2) Canadian Hemophilia Registry; Data summaries; www.fhs.mcmaster.ca/chr/data.html

(3) Canadian Blood Services 2013-14 Annual Report, p. 41

(4) Personal communication, Jean Lapierre, Directeur, produits stables et services logistiques, Héma-Québec


(6) First analysis of 10-year trend in national factor concentrates usage, Canadian Hemophilia Assessment and Resource Management System, Dr Aïcha Traoré

(7) WFH Global Survey 2012; Map of Factor VIII Use per Capita; www1.wfh.org/GlobalSurvey/Public_AGS/AGS_Factors_UIPerCapita_EN_Map.aspx

(8) Canadian Blood Services, Coagulation Products, 2014, p. 3

(9) Personal communication, Dr. Alfonso Iorio, Associate Professor, Department of Clinical Epidemiology and Biostatistics, McMaster University; Chair, CHARMS Committee, Association of Hemophilia Clinic Directors of Canada

(10) Canadian Comprehensive Care Standards: results of a self-assessment survey of the Standards by 24 Canadian hemophilia treatment centres; Canadian Hemophilia Standards Group Survey – May, 2010

A National Assessment of  
Hemophilia/Inherited Bleeding Disorder  
Comprehensive Care Program  
Services and Resources

ANNEXES
ANNEX 1: Health care provider questionnaire

Assessment of HTC services and resources

Questions to clinic

1. How many patients are registered in your clinic with the following conditions?
   - Severe hemophilia A
   - Moderate hemophilia A
   - Mild hemophilia A
   - Severe hemophilia B
   - Moderate hemophilia B
   - Mild hemophilia B
   - Hemophilia A or B & inhibitors
   - Type 1 VWD
   - Type 2 VWD
   - Type 3 VWD
   - Rare factor deficiencies
   - Inherited platelet disorders

Questions to the health care professionals

1. In your opinion, with regard to respecting the standards of care adopted in 2007, what are the main strengths of your Hemophilia Treatment Centre?

2. In your opinion, with regard to respecting the standards of care adopted in 2007, what are the main failings or weaknesses?

3. What proportion of a full-time position do you spend on the care of people with hemophilia and other bleeding disorders? (Consider care and treatment, inter-disciplinary meetings, education of patients and family members, outreach to the community and other health care professionals and continuous medical education.)

4. Is this enough to answer the demand?
   a. If yes, explain.
   b. If not, why?
   c. Do you have data or reports to support your assessment?

5. In an ideal world, what more could you do to ensure optimal utilization of clotting factor concentrates, including better product tracking, measuring outcomes and avoiding wastage, under-prescription and over-prescription?

6. What would be the principal recommendations you would make to administrators of your hospital or to other health authorities such that you could provide optimal care to your patients?

7. What would be the principal recommendations you would make to administrators of your hospital or to other health authorities such that you could continue to provide high quality care and conserve resources?

8. What other observations would you like to make?
ANNEX 2: National results of patient satisfaction survey
16 people indicated that they live between 1 to 9 hours away from the clinic which prevents them from going to the clinic without an appointment for an urgent need or a new problem. Some indicated that they therefore tend to rely more on phone and email communications or they visit their local ER. Among these, many indicated being satisfied with the phone support. In one case, they were directed to local hospital with which the HTC was in touch and in another, the nurse coordinator arranged the necessary treatment in preparation for when the patient was to arrive at the HTC.

14 people indicated that the have not yet required to be seen unexpectedly because of an urgent or new medical problem. 14 people indicated that they have been able to get rapid help over the phone as needed or questions answered by email. 9 people indicated that they are always available and quick to help. 13 people indicated that they felt they had a great team at their clinic, were very satisfied or received excellent care.

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We don't always see a doctor & have many times waited up to an hour or more to be even taken to a room to see a nurse
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All the staff have been very helpful and have helped me to educate my dentist before dental work.

When I had a terribly& lengthy bleeding issue Nov & Dec 2013, I was able to speak with the nurses at my clinic about my issues-although consistency of the nursing staff could have been better

The level of care isn't always consistent but it improves each time.

In other hospital, like Burnaby hospital, they did not have enough knowledge about my problem

I have had the nurse call me at my home using abusive threatening language.
They told me: for bleeding, I need to do injection. After hours and weekends, I can call to Emergency.
I have been told they don't need my Factorfirst card-they don't know what it is for (for clinic only).
Sometimes long time to wait
But still not very adequate
Our care is pretty professional but if the nurse coordinator is present its optimal!
Nurse coordinator would see me as soon as possible same day, often immediately after my call.
Always prompt
There has always been someone available even on weekends or in the evenings.
We can always come right away to see them if there is an emergency during their working hours
The nurses at my clinic are very flexible and accommodating in that type of situation.
Everyone is well informed/helpful and aware of your personal needs.
On only one occasion after dental surgery was it necessary for me to get assistance from an emergency doctor.
Not used other than we requested letters for travel
Always seen as a priority and immediately addressed
I usually have an appointment. I also have our nurse who will fit me in to help with the needles to infuse my child.
When I was in our local General Hospital in 2014, my daughter called unit and left a message; no one called her back so she didn't know if anyone
It's been about three years since an urgent medical problem but treatment was immediate.
The removal of adult care at my clinic has created issues of where to go in emergency situations.
The clinic is always accommodating. They always fit us in if needed.
Contacting the team nurse always results in answers or immediate action to consult with the MD and response back to what I should need to do.
The last visit was in 2012 and I received general information that was greatly appreciated.
Always visit clinic with pre-appointments
Very prompt-I'm in often and treated like family
They are always quick to respond and have accommodated me several times.
Response is immediate by telephone and an appointment set if necessary
They are amazing at accommodating and making room/time as they are usually extremely busy.
Pager # provided
I always feel that I am inconveniencing staff, disrupting their normal daily routine.
Rarely needed, but on one occasion it worked well
Weekend access problems
No complaints, they do a great job of making sure I can be seen
2. When you need to be seen by the bleeding disorder team within normal working hours because of an urgent or new medical problem, and have no appointment, are you satisfied with the care you (or your child) receive?

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19 people indicated being very satisfied with the care and attention they receive.

I feel it's a very rushed visit & they give the standard text book answers with no real bedside manner to my child. The physiotherapists have always been fabulous.

I phoned (really out of the blue) because I had a previous diagnosed blood disorder, needed dental surgery (which was not going to be done until I went to the blood clinic). I was seen immediately AND compassionately.

Have never seen them after initial visit, blood tests, etc. Most recently Feb 2014 my hematologist apparently wrote orders on my chart for major surgery-I did not see her and they were not all followed.

Very satisfied with assistance by phone received in preparation for upcoming dental work

Don't know-we usually go thru the ER

For the most part, yes-most beneficial was that our Hospital Emergency staff were familiar with bleeding issues because of our clinic hematologist

Phone calls need to be answered

See above-the care is usually delivered by the regular peds team at our local hospital, and they are great.

I believe that it would not be an issue although I haven't had the need.

I feel abused and frustrated by the treatment of our nurse

Should have ID cards on hand

My son and I have always lived outside of the lower mainland. We have made appts usually months in advance to wks.

For appointments need to wait more than weeks or months.

Haven't been in a situation like this yet

My nurses at our local hospital are in constant contact with my HTC as I get Humate-P twice a week.

I have a concern with staff change over and care experience. There needs to be improved dialogue between the hematologist and nurse clinicians in treatment and assessment of bleeding episodes. It would be beneficial of there was greater understanding of the differences in personal care and assessment and treatment experiences between mild, moderate and severe hemophiliacs.
Nos soins sont la plupart du temps faits dans un hôpital près de chez moi et ils ne sont pas trop compétents dans le domaine de Von Willebrand.

Hematologist was contacted and treatment given right away. 
They always get me in to see medical team. 
It has never been a problem. 
The emergency doctor had never administered the blood product before. 
They are booked all day, every day. We are expected to provide homecare (not fair). 
A phone call to my local hospital by them allows me to go immediately there. 
See comment above. Not happy with fact of going to other hospitals where hemophilia care struggles! I had a 6 hour wait at our emergency (unacceptable). 
I went to the emergency room (after talking to my doctor) and was told the hospital had no factor VIII or Desmopressin. I talked to the nurse about it. 
Appointments necessary otherwise you can’t see them 
Our trips into ER are quite frequently inconsistent. It is upsetting that I don’t know what treatment we will receive upon each visit. With regards to clinic, we once waited an hour to be seen by a Dr just to be told not necessary to see him. Only blood work needed that visit. Very disappointed because we drove 1 hr to be there. 
Usually can get in same day if required 
I try not to go.

3. Does the clinic provide you with a FactorFirst or other form of wallet card?

Answer Options

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Don't know what this is
I don't have this-I am a carrier mother, borderline mild hemophilia
Register with Medicalert
FactorFirst or wallet card is a waste of time and money. I had medic alert bracelet and it did not help at all. A wallet card is a joke!! No one will look for the card!!
Would be nice if we have a wallet size card
have temporary card
My clinic gave me my Factorfirst card.
I would like one for both my sons. We feel it is very important as how will anyone know the doses if in accident and we cannot say.
I really was not informed there was such a thing
Not applicable to me
I feel they should check yearly.
A wallet card with bleeding disorder info for a triage/emergency nurse/doctor would help especially for 1) unsuccessful home infusion (clotting factor mixed in syringe) 2) urgent/new medical problem.
My son is not home and I don’t remember for sure.
Only when needed to go to the hospital.
Never received one

4. Is it updated annually?

Answer Options

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answered question 271
 skipped question 76

9 people indicated it gets updated every two years and, for many, during their appointments set every other year.
8 people indicated it is updated as needed if anything changes
4 people indicated that they received their card in the last year so they do not know
2 people indicated that their clinic sends it out without it being requested.
3 people indicated not being aware it could be or should be updated annually.

But was not replaced at our visit last summer
It’s only updated when I ask for it. I don’t actually depend on it anymore, I have created my own.
My Von Willebrand is so minor I do not need to be seen annually. They update it when I am seen.
I just started in 2012
For both me and my child
But I’ve only been once
Wasn’t told about any follow-up
Very helpful
I don’t know. Next appt will likely be in 2 yrs. I know to call clinic prior to anyone coming at me with a sharp object!
The clinic was supposed to call us each year but has not followed up with us.
It is not updated annually—it should be at clinic
I do not have an updated card.
The staff is very diligent is getting me updated with the card.
Last update Oct 2011
Updated once to date
I would like a new card
In my case it’s updated only one time. For get new Factorfirst, I waited more than 3 months. After, I went to the hospital by myself and got it from the program secretary. I reminded them by myself, it’s old and need to update.
Even if updates were offered, I would be unlikely to travel to Vancouver for re-testing. Old card is durable and fine.
Not consistently-depends sometimes on timing of annual checks
Newly computerized saves time. I can leave with an updated one.
If we wish to have it updated, yes.
I only need to go every 5 years.
On ne va pas a des rdv regulierement par notre choix.
Mon rendez-vous est a toutes les 3-5 ans.
Updated at clinic visits; clinic visits not necessarily required each year if no issues.
My factor IX card is always updated by my team.
Really needs to be updated
Any changes they always send a new card
Not updated enough
They always ask about them and will always have a new one when I visit
It has been updated but not on a regular annual basis.
I do not require an annual update-only if there is a change in requirements or treatment
Hasn’t been updated since last clinic visit-2012
The nurse always asks for it and confirms it is current.
They always remind us to update and do it there for us.
The FactorFirst card is very handy, but I still have doubts on our local hospital’s ability to ‘know’ how to treat our son in an emergency. The HTC has provided training there already.
Nothing has changed
I am a hemophilia A carrier with normal factor VIII levels.
Always
The last couple of appointments, they didn’t. Went to emergency and found it was outdated.
I do not think it is updated annually—don’t believe so!
It does not seem to be.
Every visit this card is updated
Not sure
This form is actually updated semi-anually. They update when my son goes to clinic and he is seen every 6 months.
5. If you (or your child) are on "home infusion", are you satisfied with the arrangements that are in place for your home treatment (for example, telephone access to nurse coordinator, education in home infusion techniques, supply of factor concentrates, supply of infusion equipment)?

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<tr>
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9 people indicated being very satisfied and have found the system efficient.
2 people indicated not having needed home infusion yet.

A system used to be in place which allowed for patients/parents to call & order factor from any nurse. The current nurse coordinator has changed this so that parents & patients can only request factor from the nurse coordinator. This is not as convenient. In December when I called to order factor, for example, the nurse coordinator was on holiday. I think that patient families should have a choice & be able to call more than one nurse for factor orders.

Factor always is ordered in a timely manner although there are issues with picking up the factor at the hospital where it is delivered to.
Our nurse coordinator is impossible to reach. I always get her vm & can go days w/o a call back only to find out she’s on holiday, sick or just days off. As busy as our clinic claims to be, they really need a FT nurse coordinator. I have actually stopped calling her and call someone else whose title I don’t even know, but she makes it all happen. Another HUGE complaint is the amount of treatment we’re allowed. I have asked for 6 months worth as we live almost an hour from the hospital & have never been given a straight answer and have caught them in a lie—they blamed CBS which I found out was untrue. After 2 years battling, I still don’t have a good reason as to why I can’t have a larger supply or pick up @ the hospital down the street from us.

I had very minimal training.
Generally satisfied. There always seems to be a bit of confusion when I order product.
We are required annually to do a one on one clinic with our nurse to ensure we are doing techniques correctly and sterilizing correctly.
Difficult to reach the person(s) in order to order product and supplies. Seems very disorganized in the past 2 years.
Home infusion was in my opinion the best way to control AE (my blood disorder).
Telephone and email access to either nurse coordinator is quick, supply of factor concentrates is very efficient as is the supply of infusion equipment. I have been very impressed by all aspects of home infusion.
All staff are very timely with factor orders and inquiries
Am a home infuser but have not had to use the system as of yet
I can have it ordered and ready for pick-up at clinic. I would like to know more about "supply of infusion equipment"
I use all the infusion equipment inside the box-never a problem.
This was discussed but never initiated. No factor is available to me quickly at home or in a nearby clinic. Help is too far away in an emergency!
Helicopter? Ferry is on and ambulance is here. Need Factor IX here.
I have been talked down to and threatened my son would not get more factor unless he did as told by our nurse coordinator.
Find that transfusion needles could be smaller, eg extended usage in vein
Very happy with the convenience of being able to pick up factor at my local hospital
But supply of factor for travel arrangements seem to hinge on best case scenario rather than the worst!? Patients should be heard, esp if they have no demonstrated lapses of irresponsible use/behavior.
Easy to contact them. They will phone you back right away after you page them.
I am using DDAVP at home for treatment
She will be receiving home Tx but it has not started yet.
My hemophilia nurse is always there to help me in anyway she can.
The staff at the clinic are very efficient at supplying me with supplies and factor. I have never been allowed to run short.
I have recently moved and my nurse organized everything with regards to my factor, supply and pick up.
I go to my local clinic for infusion where my product is kept
I wish they would allow us more factor than approx 5-6 weeks worth. Gas and parking get expensive for multiple trips.
We have to purchase the infusion equipment and we have no medical coverage. It’s very expensive because our son has a port. 12 needles are $200 dollars.
Our local lab is very accommodating
However the supplier of the equipment doesn’t carry heprin or emla cream. They’ve also sent incorrect products multiple times. The HTC now has a nurse on call for emergencies until 10pm Mon-Fri, which has proven to be very helpful.
Home infusion program just set up-training info was good
I inject DDAVP to myself for minor trauma. I am a mild to moderate hemophiliac.
...but not always satisfied. It is really tough especially if they are under 16. yet freedom from hospitals help relieve some of the stress. My oldest usually takes fast short cuts or just claims he has done his needles.
I was well trained by the nurses in the clinic to perform "home infusion". I am given the factors and infusion equipment to do "home infusion". It is extremely rare that we do home infusion-maybe once or twice every 2-3 years. I have a cousin who usually helps since she is a nurse and she too has a bleeding disorder.
Education in home infusion techniques for other members of family would be beneficial. Also, an order form for supply of factor concentrates and supply of infusion equipment (pdf or on-line) would be helpful/useful.
Very fast response time
My factor is in the fridge at home. Hve been taught how to use - take it to local hospital - only a call from HTC team gives me peace of mind before infusion. They do not know how to make it up.
No problem ever - even reminder call for holidays.
Always quick response to my requests for product or supplies.
We always have lots of supplies at home. And if we are having trouble we can always page the doctor on call.
Mild hemophilia.
They are great, they always get back to you with the answers you need
Used for travel, as my need for treatment is irregular
I have what I need and our nurse is always quick to respond.
Exceptional help from team in logistics and service
It is great to be able to go to the blood bank after hours to pick up factor, allows for continued care without having to miss work.
I have not ever made such arrangements

6. If you (or your child) are on "home infusion", are you advised to provide a diary about your home treatment/bleeding events?

Answer Options

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<tr>
<td>Yes, and I fill out the diary regularly on EZ-log, Helitrax or</td>
<td>29.0%</td>
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<tr>
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<td>20.4%</td>
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16 people indicated 'not applicable'
Always fill out the diary (maybe not always in a timely manner) way easier with the online services now.
I’ve never been asked for it, so found it to be a needless waste of my time, so I stopped.
My home treatments are very simple: injections then go to clinic to have blood sample taken.
My bleeding are under control of hormone replacement therapy for 26 years.
Was not aware the diary could be filled out online
There is no follow through and it is very old school (paper). Very inefficient, would prefer electronic process online
I often forget to make entries into my log because of memory problems
Would be nice if our clinic used EZ log or any digital log
And email to clinic
I am sporadic with my submissions.
We tried the EZ-log and it wasn't very intuitive so we prefer the paper.
I keep an excel doc
On an excel spreadsheet
I then regularly scan the diaries and email them in. I look very forward to using the i-CHIP system.
I inject infrequently, maybe twice a year with DDAVP. I don't see the value in recording these events.
Since we do not do this too often, we rarely do it. I do keep the stickers/labels of his product used in the diary.
I try to keep up.
I keep track of bleeding events with a period app for my iPhone and keep pictures if needed.
No need to have to provide diary daily only need to go to hospital.
I used to fill out papers but am so glad they came up with EZlog
Irregular bleeding incidents so go to HTC except when out of province.
Actually I submit electronic file (Excel) when requesting more factor
I use iphone app to track.
I don’t think the comp care centre is reviewing these records. There is no contact from clinic during periods of high usage to cope with serious bleeds or trauma.
I use an Excel spreadsheet
Diary is done via emails and not on paper

7. How often do you go to the comprehensive care clinic for a regularly scheduled check-up?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Every 6 months</td>
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</tr>
<tr>
<td>Once a year</td>
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</tr>
<tr>
<td>Every 2 years</td>
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</tr>
<tr>
<td>Other</td>
<td>13.9%</td>
<td>47</td>
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</tbody>
</table>

answered question 339
skipped question 8

8 people indicated every 3 months
11 people indicated as needed
5 people indicated only when requested
4 people indicated not having been invited or offered
4 people indicated very 5 years

Sometimes once a year but one time every 2 years
Waiting for referral re connective tissue dysfunction
Yearly but from my last appt is now required every 2 years, but if problem arises call office without hesitation
I have never missed a check-up. I'm now 40 years old.
They have never set up another appt-but they said they would see us yearly
I went for 2 years 4 visits and the whole time tested negative, but they still treated me
Used to be every year but Dr. retired and a replacement hasn't been hired so I've not had a checkup in more than 2 years
I only go to clinic to get a new order of medication and supplies, several months
A lot of the time timing didn't work out - moved back to lower mainland, not as far - I get driving anxieties.

We are invited to attend the Wednesday clinics but opt not to because of our distance.

Have been going once a year but will probably go less now

More, if there is a new medical issue or complication.

Every 6 months for 9 yr old, every 3 months for 7 month old

Been only once

I have a mild hemophilia so I am not asked for any check up

Should be annual but ends up every 1 1/2 yrs or so

Seldom, not needed luckily for me

When availability and timing applies

Travel expenses - I do however use the Hemophilia Society to get reimbursed for gas allowance but takes awhile to get back money

Initially once a year - now apparently a 2 year program

Tough to get to from our town to Vancouver, especially when clinic days are Tuesdays

Once or twice a year

I have no concerns. The clinic was offered in my area at 2 year mark, but would require me to miss work and I have no concerns.

Other, if injured

Sometimes more often. I may not be available due to work, etc

Every 2 or so years

The team has been to my hometown hospital a few times for clinics and I have seen them when they were here. I live 5 hrs away from the clinic and I have only attended a clinic a few times except when I was hospitalized in St Johns.

This has varied somewhat depending on how recently he has been seen for a problem.

Once a year sometimes longer

Mobile clinic - I used to attend the mobile clinic but we're moving to adult care, I haven't been invited.

Sometimes more often

With a pediatrician for follow-up three months following HTC apt.

Once a year would be fine for us

First time

Usually done by tele-health from my community to HTC

Try to go annually

Depends on if health concerns are increased or have sudden or new concerns, then maybe a second visit would be required.

They care more about that because you have an appointment. Unexpected bleeds are not that easy.
8. At the time of your regular check-up, which clinic members do you meet?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
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<tbody>
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<td>Nurse</td>
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<td>Physiotherapist</td>
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<td>Social worker</td>
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</tr>
<tr>
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</tr>
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</table>

17 people indicated dentist
9 people indicated rheumatologist
5 people indicated orthopedic surgeon
5 people indicated genetics person
5 people indicated Students-Residents
5 people indicated seeing administrative assistant-secretary-receptionist
4 people indicated seeing personnel related to research
3 people indicated ob-gyn
3 people indicated lab personnel related to blood work
3 people indicated coordinator and 1 Hemo Ont rep.
2 people indicated pediatrician

My next appointment is in July 2015. I’ve phoned and tried to have it changed but never can get anyone. I will try again.
I have had surgery in 2013 and went to clinic after 10 days in hospital and follow-up in January. Regular appointments are in April.
Travel is sometimes a problem.
No time.
Lorsque j’ai besoin d’une chirurgie
Rarely.
Started off annually. I have not gone to a CCC in 3-4 years.
I always attend.
Never. Only go when needed. Last visit was while pregnant-requested to attend by obgyn/obs
Wish to cancel
Haven’t been for a few years
The social worker presently at the clinic has indicated a lack of understanding of hemophilia. Several years ago, she pointed to Judo and other martial arts as a good form of exercise! We explained that this is not a recommended activity for severe hemophiliacs. Thorough training should be a must for all clinic staff, to avoid giving misinformation to patients & families. The same staff member has also (about 2-3 yrs ago) made critical remarks about another hemophilia family, identifying them by mentioning the number of children in the family and their town of residence. This is not acceptable, supportive of a positive, respectful clinic/community.

We spend more time waiting in between members than actually with them so feel this too is a waste of time. These recent two visits were my first. I was told I could see the social worker, physiotherapist if I wished and if it was needed. I was always asked if I wanted to see a physiotherapist but I’m in excellent physical health (I exercise 3x a day, 7 days a week) I am quite satisfied seeing Nurse at the clinic. She is knowledgeable and thorough. I do not need to see the physician. 1st visit only, not sure about follow-ups
The nurse was wonderful
I have not seen a physician for years
Did receive clinic with Dr in Jan 14
Don’t have appts
Never had a check-up
My son only sees the Dr and nurse when we go for check-ups
We sometimes see a social worker in Vancouver, but not when the team travels to our community 800 km away. The social worker service is also not essential for us.
Administrative assistant. The clinic members coordinate their time which makes each visit very efficient.
Usually such meetings is without results
The entire team are exceptional and dedicated to their patients.
My physiotherapist is awesome.
Very often other team members ie social work, physiotherapist are not available
Rheumatology was part of the team-she was later deemed unnecessary and untrustworthy so no longer welcomed.
Requested social worker once to talk about the 911 call from the school and ambulance ride
No one else is required for my care.
At times feel pressured to give blood for their learning.
Very well organized.
Very kind staff
Other: Rheumatologist. There are no more social worker and physiotherapist.
Not always a physician as the current nurse is a nurse practitioner.
We do see them, not necessarily all of them on the same visit
They all at some point during appointment pop their head in even if not scheduled to see them.
9. Are you satisfied with the arrangements that are in place for your check-up? (Please consider such things as: appointment notification, length of time in clinic, wait times, preparation instructions, explanation of procedures/tests)

<table>
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<tr>
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<th>Response Percent</th>
<th>Response Count</th>
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</table>

Total answered question: 344
Total skipped question: 3

13 people indicated being satisfied noting their teams are well organized, efficient and 15 people indicated wait times are too long (comments kept below)
8 people indicated length of appointments are too long in order to be seen by everyone

In the past, apppts have been far too long. This was better at our most recent appt which began later and ended sooner than previous apppts. I think that lengths should be kept as short as possible, especially for children.

Lengths of apppts can sometimes be too long. Review of child’s history by medical resident can be very time consuming and tiring

I truly see no value in our appts @all. We get more comprehensive care from our family doctor @our annual visit.

I was notified but knew my check-up was due so called to book my own appointment

Some miscommunication between Dr. ’s office and clinic in scheduling of bleeding time test initially but resolved when I called in. Excellent apppt notification, long time in clinic but expected it to be. Family Dr. began process for referral to HTC doctor summer 2013. In April, 2014 was my 1st appt. Previously met with HTC doctor on in Feb, 2014 and he ordered addtl tests before referring me to clinic. It was difficult having to go off medications for 2 sets of tests, but at least the clinic had all the test results before my 1st appt and a comprehensive medical history.

Much more efficient now than in the past

There has been many changes of docs and nurses & I think we’ve been lost. Sent email a week ago and still no one has responded.

As I said above, they still made me go through everything even though I tested negative.

Long apppts but there are several people to see

Typically a long wait in the clinic. Apppts usually behind

Just see my physician now

I have not even met my new doctor
I would like email notifications of upcoming appointments. Email makes it easier to connect. We are also happy that they are now willing to offer outreach clinic in our community once a year. Wonderful-they travel to PG-I am so thankful for this.
Wait times could be better, only morning 8am appts available usually.
Time could be managed better-often have to wait for 1st appt and then also wait between hand-offs
I am a low maintenance hemophiliac as I seldom have joint or muscle bleeds but nosebleeds. Not scheduled regularly or I would go
Don't go often enough
Should be informed of prescription list and pain management techniques eg anti inflamatories
They are late for appointment time. Physiotherapist and social worker told me that some patients are waiting more than one hour.
The last 2 years the team has travelled to my location rather than me travelling to Vancouver-great!
My son had to miss his class
The wait time and length of time in clinic can be very long, sometimes up to 3 hours, 1 1/2-3 hours
Wish they would explain procedures, tests. I always have to ask for explanations. Everything else is good.
Wait time could be shorter
But still not adequate
The clinic team members often do not know who else will be seeing me.
Our care at clinic days is pretty good but sometimes it seems waiting times are too long.
Lors des rdv temps d'attente trop long- pour voir le MD, plusieurs hre, une des raisons que l'on ne visite pas souvent
I have not had to go for check-ups - stable.
I am satisfied but at times there may be a long wait time.
I feel that all team members should be available during visits
Length of time is extensive. There is no set time for the appt so we usually need to wait @4hours.
Seems delayed and unorganized most of the time.
One concern-information re results of the clinic observations re my situation and blood test results slow to come (2 weeks and waiting)-much quicker in past years
Excellent pre-arranged appointments which never have taken more than 2 hours with blood work included.
Most times there is too long a wait between meeting with clinic members.
Visits can be quite lengthy and redundant with 2 children being seen every 6 months. This last one was 4.5 hours, a little ridiculous if you are in and out
Infrequent appt times-"we have an opening 6 months from now or 9 months from now"
I live in St Catherines - it would be nice if I could just go to the hospital here to be seen.
Sometimes wait times can be long. However I do understand as we are in a hospital setting.
Lorsque j'ai un rendez-vous, je passe à l'heure indiquée.
Very long wait times
Wait times if can be reduced-it takes half day min. for 30min appt
Wait times are generally about an hour even when booked early in the mornings. Appointment notifications are generally about one week prior by phone.  
My most recent annual checkup with my new Dr. was by far my best appt.  
Too far to travel

10. Are all the questions you have and the issues you raise at your regular check-up addressed to your satisfaction?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
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<tr>
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<td>8</td>
</tr>
<tr>
<td>Not applicable</td>
<td>5.5%</td>
<td>19</td>
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Somewhat—at the time of our last clinic visit, we were glad that our request for a shorter visit was accommodated and that our suggestions about ways to possibly improve the way clinic days are run for example, were heard,  
Awaiting referral to connective tissue dysfunction specialist for further investigation and my cardiologist has ordered test too  
I understand they don’t have all the answers but do their best to answer  
The doctor we saw the 1st time was a bit rude  
Visit to physician—yes definitely  
Any follow-up information is quickly sent out too.  
Very satisfied  
Nurse raises her voice and threatens not to send product.  
Uncertain as to overlaps with family physician  
I seen my physiotherapist several times but she did nothing. I din’t get physio help. Within three years, my specialist refused to make for me an appointment with orthoped.  
I don’t want to cause I don’t really understand what’s going on  
VERY informative  
Usually but not always due to needed input from ob-gyns re birth control, menstrual bleeding, etc  
Very good in every aspect and take the time to answer all questions and any issues.  
Everyone is always very helpful.  
I find the entire team very helpful.  
HTC clinic is awesome.
Most of the time. Hard to remember everything from the last 6 months.
Yes, I get detailed explanations every time.
Always follow-up on issues.
Always.
I've always found the team helpful and informative.
Physician, nurse and physiotherapist ensure that answers are professionally delivered and explained in layman's terms.
My HTC is excellent in this :-
They weren't always addressed. As mentioned above, my recent appt and care changed my opinion on this.
Mostly
They take great interest with my issues

11. Are you satisfied with the physiotherapy and orthopedic services that are available for the management of your joint problems?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
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<tbody>
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<tr>
<td>Not applicable</td>
<td>46.2%</td>
<td>157</td>
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</table>

answered question 340  
skipped question 7

10 people indicated a high level of satisfaction
5, surprisingly, indicated not being aware this service existed.
4 people indicated they have not yet required this service

As mentioned before, we have always had a great experience with this team and feel they care for us as a family and not one more patient to push through
Physio does not appear to receive much training regarding joint health and bleeding disorders
I have a wonderful physiotherapist already
We haven't had any joint bleeds yet, but the physio that we meet is great.
I believe my eldest son may benefit with the physio between his 6 month appointments but there is no availability in our rural community.
We have a hard time paying for helmets as our son grows fast and I am not covered through work.
I have one problematic joint but it is not arthritic.
Joints seem ok according to physio
Few problems to note. Will eventually need THA revision
Physiotherapy weak
Orthopedic for me made appointment with rheumatologist. I appreciate it. Rheumatologist is perfect specialist.
Friend and 4 other people got his surgery canceled twice because of lack of nurses to administer product after surgery which I found disheartening
I have had multiple joint surgeries and the care I received was exceptional.
My physio is a great help. She provides exercises, options for mobility, help with pain, etc-she’s great!
Accessible even at short notice, friendly and good follow-up
Not seen on a regular basis
Not often I get the services-I can’t be making the trip very often , no fault of the clinic
My physiotherapist provides lots of information always; takes time to talk about concerns and ALWAYS follows up.
Sometimes I don’t agree with her theory on his pain or bleeds.
experience a knee surgery in last year.
Services have been available for about a year-the physio My physiotherapist is great-very knowledgeable and professional
Having physio available has made great difference in preventing joint bleeds
Rheumatologist provides service for urgent medical procedures, it is not easy to book an appt
This could be improved.

12. Are dental services offered at or through your clinic?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
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<tr>
<td>No</td>
<td>27.7%</td>
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</tr>
<tr>
<td>I don't know</td>
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<td>175</td>
</tr>
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</table>

*answered question* 343

*skipped question* 4

11 people indicated not being sure if this service was offered or having discussed it

Take care of dental services locally at our family dentist
I have our own dentist and the clinic team is aware
If there was, we wouldn't use it
But I didn't bleed at all after my tooth removal
I already have a dentist
Would be great!
The last time I asked it was, I haven't asked lately though (no need)
Our dental work is done thru the hospital and they ask the hematology clinic or input before any dental work is completed.
Dentist is present at the yearly clinic, have never been to a dentist at the clinic for cleanings, extractions, etc
I have a regular dentist who is not at the clinic. The dept of dentistry is located in the same bldg as the clinic but I have never been told to go there.

Not required for me
Have worn a full set of dentures for about 15 years
My dentist contacts clinic prior to a procedure.
We recently had to attend our local hospital for DDAVP prior to having a tooth pulled. The hospital seemed to lack info on DDAVP and what it was for. Then driving to the dentist and getting the tooth pulled at the hour mark was a bit concoluted. There must be an easier way.
We don't use the dentist at our clinic but one is offered.
My son has had dental services arranged in the past for problems with his teeth/gums. This service was provided in conjunction with the nurse coordinator and it was excellent.
That would be a welcome service provided, one stop so patient is comfortable and confident with dental procedures being done.
Yes, I got Factor IX infusions before dental surgery. Dentist was satisfied with results.
I found out by myself and informed about that to the hemophilia program.
Never had dental surgery but would consult prior to if necessary
They were but I didn't like the dentist because he wasn't very good at his job so I didn't continue with him.
It is done good
Being at a hospital, there is a dental clinic in the same campus, but not part of the clinic.
If surgery is required, yes.
This is something I think we need to have at our clinic because lots of people can’t afford to see a dentist when they need one.
We use a regular dentist.
See regular dentist and consult with hemophilia nurse
I don’t know-but in need of dental services but can’t receive it because I don’t have insurance.
I did receive information for dental services and medication in case of oral issues, but was not seen by any dental services.
I know there is a dental program at Janeway but so far it has not been suggested that my child require its services
However they have not been needed-see our family dentist
It would be a great benefit since dental procedures are a big issue, despite regular cleaning and check-ups several times a year.
Have met with members of the dental team but have never discussed sevices offered via the clinic.
Most times we see a dentist at a clinic visit but we do have our own family dentist and always consult with the bleeding disorders clinic before any procedures are performed.
I have full set of dentures now.
My factor level is around 17-20 and so it has not been necessary to have any anti bleeding therapy.
My hygienist is knowledgeable about bleeding disorders & the hemophilia clinic has been great for consulting with my dentist before I have any dental work done.

I have a dentist I attend regularly, This is not a service we require.
We go to a private dentist. All are aware of bleeding disorder.
I see my own local dentist and never asked for services at the clinic.
I have had them request a dental surgeon through the clinic for teeth issues - not at hospital but private office. Referral came from clinic. Could be good to have a referral service to dentists with experience treating individuals with bleeding disorders - person can choose to use service or not.

They are available but I have not used them.
Not interested anyway. I have dental coverage through work.
The clinic originally provided a list of dentists when I was looking for a new dentist about 18 years ago.
Dental services would be welcomed!
I have coverage through retirement pension plan.
Does not apply for this part of the question.
Although clinic knows regular dental care is being dealt with in our community - paediatric dentist. * on two occasions we did require to be seen by hospital dentist for extractions - we made the inquiries.

They are but we chose not to use them - we have a great dentist outside Sick Kids
We have recently seen the dental clinic as suggested by hematology clinic but the dentist did not seem to care either way if we continue seeing our regular dentist closer to home as long as it’s not a special procedure that needs to be done.
I home infuse and go to a local dentist
My dentist is aware of my bleeding disorder and if at some point it is necessary to involve the hematology clinic, both are aware of my needs.
I have no real teeth

13. If you use the dental services offered through your clinic, are you satisfied with them?

<table>
<thead>
<tr>
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<th>Response Percent</th>
<th>Response Count</th>
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<tr>
<td>No</td>
<td>21.7%</td>
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</table>

31 people indicated 'not applicable'

Do not use dental services
They are very good.
We just go to our family dentist
We have used the dentist at the Children’s Hospital but it was too limiting given we live so far away and we are more comfortable working with a local dentist for regular dental care and cleaning.
Have not used dental services as of yet
Never used
No dentist services available at our clinic.
Very good team.
Except for admin staff we dealt with for the appt-one person
None
Have only needed questions answered
Haven't used them other than when they check up at clinic
I have never used dental services thru the clinic
I have my dentist locally
Have used in the past, she is still my dentist
Never used/know this service before.
Used only once to remove one wisdom tooth
Services are not offered
S'il y a les soins dentaires, je ne les utilise pas.
We had to make the appointment & coordinate with clinic for treatment - there were no issues.
Never used the clinic's dentist since we have our own

14. Are the costs of dental services covered?

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<thead>
<tr>
<th>Answer Options</th>
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<td>112</td>
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<tr>
<td>skipped question</td>
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</table>

20 people indicated 'not applicable'
7 people indicated not knowing or being sure if and what is covered

Partly
Work dental plan
I use Alberta Blue Cross for dental insurance coverage
By personal benefit plan
Minimal check up is covered but any work would not be.
The majority of dental services is covered, but we pay a percentage through our dental plan for a pediatric dentist.
Covered by extended medical insurance through our employers
I have company insurance.
I do not get any except at my dentist's request.
I have disability benefits.
I have dentures.
But only as my child is young/minor.
I would discontinue social worker and psychosocial workers (no need for) and take funds to cover dental costs on patients.
I am on SA
Partial - Blue Cross (80% covered)
For surgery in hospital, yes.
I have insurance
I believe so but have not had experience.
None
I have coverage thru work 80%
Covered by MSI Blue Cross
Use drug care coverage
Through our personal work insurance
I have requested but no answer.
ODSP
I have requested but no answer.
ODSP
Partially through work
Not required-I have dental coverage
My work insurance covers all costs.
Need dental insurance through our employer which we did not have; paid out of pocket for dental visit.
Covered thru our work dental plan
My child is on ACSD
I have benefits thru work
Thru my husband's work plan
Through employee benefits
Private insurance through employer
I have private insurance.
My company pays 80% of the cost
15. Do you have access to a social worker if you (or your child) need one?

<table>
<thead>
<tr>
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<tr>
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<td>19.8%</td>
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answered question 339
skipped question 8

6 people indicated they don't need one

If I felt I needed to access addtl resources I know I just need to ask and the team will help and refer me to some.

The children's clinic has not been able to maintain a social worker, but the social worker at the adult clinic was available and more than happy and VERY knowledgeable to help.

He is very good and accessible.

I asked our social worker for study results on aging but he promised and never delivered anything.

I don't have membership to hemophilia program. I sent application and didn't get answer.

He was very very helpful and provided info about scholarships, etc.

Exceptional

They are available when we need one; the hemophilia nurse sets it up to see worker.

I have not felt the need or made inquiry about this
But I would assume so

I am sure one would be made available if I made a specific request

Excellent. Our child has been bullied due to his bleeding disorder and she helps him cope.

I would seek one in our city if need be.

Our SW is lovely.

Never met her (?) (New one since 2 years)

I head that we do have a social worker in the clinic but I never used this service before.

Never had to use one
Could be great to have regular phone 'visits' with new parents to see how they are doing -- don't wait for the parent to call the SW, make a weekly (?) call simply part of the program to keep lines of communication open. Can lower number of calls as parents become more comfortable with their new BD child. Great way to lower stress and allow gradual supported learning.

Don't know for use, but I am sure they are.
I think they do have a social worker-we have just never needed one.
We have heard there is a social worker as part of the 'team'; however, we have never been introduced or asked if we need to meet with her.
She is wonderful
I will be asking the Dr. at our next clinic visit next week if necessary.
Never have felt the need for social worker input.
But probably it could be arranged

16. Do you have access to a psychologist if you (or your child) need one?

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Thru work employee assistance program. Not thru clinic.
If I felt I needed a referral, I know I just need to ask and the team will help and refer me to some.

Not thru the clinic. I had to go thru Alberta Mental Health Services.
In Vancouver-not sure about in Victoria
But I think the wait list is long.
Finding a psychologist is very difficult where we live. We did see a doctor (psychiatrist) through Children's but finding a child psychologist in our area was very difficult.
I think a psychologist would be an asset as my son has had resentment and feelings I was unsure how to handle with regards to frequent infusions.

I don't think so, but this would be great
Have not needed one
I don't need psychologist and I didn't asked.
17. Are you satisfied with the psychosocial services that are available at or through your clinic?

Answer Options

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<td>74.4%</td>
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12 people indicated not knowing these services were available or having been informed about their existence.

*Likely available if requested*

*Would rather use funds for dental costs and discontinue psychologists*

*I would think only 'private' psychologist.*

*We were asked if we wanted to see one when we had an issue with our son, but we optend not to*

*Again, this has not been an issue to pursue*

*The HTC appears unable to retain psychologists-they are like trying to see God or Jesus Christ in the flesh*

*Haven't needed one though*

*Have used the services of a psychologist due to learning disability*

*Have never met with a psychologist thru the clinic*

*Have never needed one*

*Never asked.*

*I know there is a psychologist to help if I need.*

*Through our personal work insurance*

*I would think if I needed such an appointment, the clinic would help.*

*Did not require this service*

*Never been discussed - never been asked if we need access to a psychologist.*

*She is amazing*

*I have access to one & will look into seeing if it is necessary for my daughter to start seeing one herself.*

*If I did, that would be beneficial*

*I need to realize they can only help you feel better & can't "fix" your problems (unfortunately :))*

*I am happy with who I see.*
18. If you or your child recently moved from pediatric care to adult care, were you satisfied with how the clinics helped with the transition?

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We look forward eagerly to transitioning to the adult clinic. For children past a certain age, esp teens, I think that young people should be able to choose whether or not they wish to remain with a pediatric clinic.

My oldest son graduated to adult care and he found the adult clinic to be not nearly as accessible. When I first came to program, I was adult.

My son still loves the pediatric care he was receiving, as opposed to adult care

I have not been contacted since I moved to adult care in 2012 (last visit was pediactric clinic)

This year will be our last pediatric visit

I started with the clinic at 16 & I am now 19-I didn't notice any changes if there were any
I have a 24 year old and a 10 year old. My oldest felt really lost; wanted help along - weren’t allowed.  
Not yet applicable-will transfer in 2014  
Services now provided through Child pediatric care: would like to see specific adult care clinic  
Two positive experiences in last five years.  
Haven’t been to the adult clinic yet

19. Does your clinic team provide information and advice to other health care providers (for example, pediatricians, family physicians, dentists, etc.) who care for you (or your child)?

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<td>53</td>
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<tr>
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answered question 343  
skipped question 4

9 people indicated they were not certain if this is done or not and what gets shared.  
(comments kept below)

Always communicate with our local doctor and send him updates after our yearly appts
I believe they send clinic visits to our family doctor, but do not believe they communicate with our dentist.
But last surgery Dec 2013, South Health Campus did not follow instruction. I ended up in a 5 day emergency stay due to pleural effusion. was very sick!
They have been amazing at this and have made a real difference to my care.
I believe so-my recent surgeon commented he followed the clinic’s recommendations & I bled excessively-believe he was following up with this.

Team sent note to my family doctor and cardiologist (needed his input re DDAVP) They are available if dentist or other-ER, etc_ need advice. Have prescription and instruction for upcoming dental work.
All check up results have always been sent to my family dr
I don’t require any advice on this subject
When requested
This would be nice
Have letter to carry product for travel, etc. Need to explain condition to every doctor/dentist I see
Whenever a procedure is to be performed only.
Clinic provides my physician with all information/results of annual check-up
When needed only
They are good to do this, although she has been only once and it was in 2006
This is something that needs to be done better. The GPs don't understand and aren't communicated with.
As the mother also with VWB 2A, I find HTC adult care clinic better in this regard.
The clinic team has been exemplary in providing information and advice to our dentist and willingly share information with our pediatrician.
Often our doctor and pediatrician find Children's Hospital to be slow to answer or not always communicate
Never asked
Have provided information for pre-surgical (peri-operative) procedures.
This is done very well! Excellent outputs from nurse coordinator.
I don't think so
To family doctor
Uncertain as to the amount of information provided
Family doctors always found by myself. Once wrote about that to the program secretary, They sent to me website.
I showed card to my doctor.
This should be done in all situations. Not all other care providers are necessarily and sufficiently informed about hemophilia issues.
Other specialist of which I have many
They have in the past
Are very willing to work with (talk to) our regular pediatrician.
very much so, no problems there.
My children have req’d treatment for other medical conditions and the hematologist has consulted on their condition as a team
My clinic introduced me to a local doctor when I moved to a new town
My family doctor receives updates on bleeds.
when asked or required
Unsure
We have had issues due to the fact of provincial space, but I believe it to be on my family doctor's side not the clinics.
They have all along.
We see a pediatrician every 6 months, alternating with HTC visits as well.
Reports sent to family doctor. Excellent when travelling, providing factor & notifying me and the area that I am visiting in case of emergency.
preparation for childbirth, they have let me know my options
And they're great at it! I've never had any problems making sure that my other HCPs are on the same page with my bleeding condition.
Not aware of any.
I believe so! I think our pediatrician did receive some info from our HTC
Other health care providers have not asked for additional information (aside from what I have told them).
Yes, always very helpful.
I have used clinic for referrals in Hamilton Health Team settings as any surgery would need their support for factor, etc.
Have not used this but I am quite sure they would.
Not recently, but they have in the past.
The doctors actually did a seminar for the dentists in our area to educate them on bleeding disorders.
Written format information and access if they need to talk
Clinic summary is sent to family doctor. Dentist has contacted clinic for info in past when there has been concern.
Sometimes our pediatrician will receive faxes of our daughter’s admission into hospital but not each time.
Again it would be very helpful if they did. Not sure when/how they do this
Great help from team in communicating with my extended health care team in a small town
When needed, ex needed operation, the necessary communication is managed very satisfactorily
I usually request them to fax it
I believe so, but will check with my family physician at my next opportunity

20. Does your clinic team provide information and advice to people in your community (for example, teachers, daycare workers, employers) if you request it?

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<tr>
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14 people indicated never having requested or used this service

Former nurse was very efficient in this area (20 years ago)
That will never happen!!
Could be done better
Nurse came to our daycare and talked to the supervisor
They regularly offer to provide information, advice or visits to our sons’ teachers.
Social worker said I will help you find a job. But didn’t help.
I’m sure they would if I asked them to
They give booklet for guide
They will if needed
Probably
Parking & accessing the clinic is by far the biggest issue raised by patients.
25 people indicated parking is too costly (some comments kept)
19 people indicated finding or accessing the clinic itself is problematic (some comments kept)

I feel strongly that we shouldn't have to pay for parking at the clinic. We do get parking passes if we ask but sometimes I forget.
Clinic is quite difficult to find and information services were not helpful and did not know that the clinic existed.
Clinic keeps moving the location.
Parking is limited and very expensive. Mom drove me. I use a walker. Clinic staff provided excellent directions for access with walker (or wheelchair)

Parking at times, isn’t an issue though
Downtown Edmonton
A long walk for the products
Clinic was poorly constructed with lots of wasted space, parking is a joke, not to mention the elevators.
I take the LRT—it is efficient
Need to see doctor more regularly
More parking would be better, but the location is downtown so less parking is expected.
Parking can be troublesome sometimes but it is due to location (downtown Vancouver)
Would be nice to not have to travel so far to get to a clinic
Close to Skytrain, parking underground and located in downtown location.
Can’t get product or return calls in a timely manner.
The cost of parking is so high and I want to ask you to recommend them to cover this cost.
It was great they offer a clinic in my community too (Vancouver Island).
Parking at our HTC is lousy—not bad for me now but horrible when mobility was limited.
The people not involved directly with the chapter or care team usually give a hard time—as to why didn’t you bring your own wheelchair, you should have been here earlier
I have never been informed of parking my car or refunded.
Better than ever
Hospital parking lot here is a nightmare! Not enough spaces
Paying for metered parking is stressful when attending appointments. Time runs out on meter.
Parking is very poor. Signs should be placed in elevators or outside of elevators to indicate on which floors clinics/services can be found.
No issues here.
Parking is difficult—we will usually get dropped off to avoid parking
The clinic is housed in the Health Science Centre, which is the most labyrinth, user unfriendly environment in the province; parking is always a HUGE issue
Parking is ok I usually find a place to park with no problem
After hours I must report to emergency
parking is CRAZY! otherwise everything has been fantastic!
Parking is bad as construction on a new parking lot has been underway since we had our son.
But they do stamp the parking card so no payment. It’s just not good right—building an addition to the hospital
The parking is terrible. I am unaware of any after hour entrance.
Parking during the day is a real challenge - large hospital with limited parking during the day.
But it would be great if parking were free! Also the space is a bit small, I’ve had to wait for a spot to open up before, which made me late to my appt.

Not happy with after hours in emergency at children’s or General Hospital. Feel so alone. No compassion or experience. Everything is pretty clear.
The parking is always tight.
Parking is so expensive: $15-17 a time - not sure where I would go after hours - would need another hospital as McMaster is for children.
Parking is too expensive - could really impact a family that needed to visit frequently. Increases the stress of situation; can CHS fund a parking program?
Generally satisfied, but like everyone visiting a hospital, parking is always an issue, both finding a spot and cost. (I’m aware CHS would help with cost but parking just seems excessive).
Removal of adult care at our Hospital has created issues in emergency care.
They recently moved and now parking is more affordable.
Parking is expensive, especially for parents who may need to spend more than just a day at the hospital. It creates a lot of financial stress.
Wheelchairs at our hospital are useless for self-operation because they have automatic brakes that require a ‘pusher’ to release.
Shuttle service should be provided from parking lot to hospital
No access during nights/weekends other than emerg dept
But to be clear, parking lots are sometimes expensive and a fair walk/distance when disabled.
Use subway/public transit

22. If you (or your child) need to go to your clinic for help between your regularly scheduled appointments for a non-urgent medical reason, is it easy to book an appointment?

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15 people indicated they never had to do so

If possible, I'd prefer to wait until after hours and go to emerg instead. We have been told in the past that they're "too/very busy"
I usually just telephone with the problem.
I don't know-I have not had to do so. I called nurse (for followup after cardiologist appt and prior to dental work) and she was excellent to deal with.

9 hour drive
Fairly
Difficult to get an appt. I have waited 3 years between appts.
As an adult, I am only permitted once every 2 years
Limited availability
Somewhat
I would think they would fit us in, but we have not required an appt in between scheduled visits.
The clinic team always makes accommodations to get us in for an appointment.
But we have to travel 3 hours
Don't know as it is too far to get to one
Long distance travel
They are very busy with "bleeders" and I do not go there casually.
Not awlays- particular staff seem to be away different days of week-may help if everyone had a regular schedule
If I call the clinic they are always available to talk to me or will call me back in a timely fashion
Have to travel 3 1/2 hrs to get to clinic
Live outside the clinic area and have never tried to make an appt
We don't- 6 hrs away
Would contact pediatrician recommended by HTC that we see
Yes, always get immediate assistance and results
Not sure; I only go with appointments or to emergency. Usually try to solve it out ourselves.
Booked through nurse coordinator.
I feel it has been easy in the past.
You do have a bit of a wait. They only run 1 clinic per month. If you need to see the nurse it is very fast.
Easy to book but usually weeks away.
Just call nurse and set it up
Had difficulty booking appointment, not clear on who to call
I have local services
Long wait times
23. How quickly are you usually seen?

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</tr>
<tr>
<td>The next day</td>
<td>5.5%</td>
<td>17</td>
</tr>
<tr>
<td>2 or 3 days later</td>
<td>14.9%</td>
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**Answered question** 309  
**Skipped question** 38

26 people indicated it depends on the issue/emergency adding it is usually fast: same day or next:

- They generally call back within 24 hours and if I need to go in I get in fairly quickly.
- Reached nurse by telephone and she consulted doctor and called in prescription for upcoming dental work within the next day.
- Everytime I have requested a visit it was and has always been on the day I requested.
- Still waiting a week later for a call back.
- 4 to 6 weeks have had a hard time convincing the clinic nurse that I need to be seen.
- Cannot be seen.
- When works for us usually.
- It has been from the point of travelling from out of town so the clinic accommodates our arrangements within weeks.
- For non-urgent medical reasons.
- Unsure-but they are quick.
- If possible they want to see us immediately, even if it's non-urgent reason, but there are cases that they need to address the needs of others seeking urgent attention.
- Haven't been there for help in a while.
- I usually call to notify of my situation.
- Very accommodating to me! Nurse is amazing and tireless.
- I have never needed to as I have a very mild case of hemophilia. I am lucky.
- One week.
- Need to wait more than weeks or months.
- But I can always go to hospital ambulatory daycare, where I go twice a week.
- Sometimes depends when the clinic (physician) is seeing patients.

However, I have a concern about the after hours on call phone service being eliminated. This is valuable. In the past, I have had ER treatment given using the wrong protocol (ie intravenous instead of subcutaneous). This resulted in a shock response driving home. The on call nurse had not been consulted by ER. If the on call service was eliminated, the potential for these incidents would only increase.
When requested, appt times are reasonable
We are seen pretty fast
Next available appt
Or the next day
It could go longer according to circumstances
When in town they always accommodate me. I fly in for appointments.
I don’t know
Since I live a distance from the clinic, I’m happy with the time. Usually, they look after my needs via phone.
Never needed to
Can’t remember but very quickly
Never needed to
I would attend emerg in my local community
Immediately or same day
It depends on the issue & who I’m willing to see about it. My regular nurse only works part-time & I’d rather wait to see her than explain my whole history to someone for a simple question.
No later than same day
The services are usually excellent—no negative comments at all
Clinic is only held once a week on Wednesdays. These check boxes do not take this into account.
They saw me 1 week after I left the hospital.
Schedule a day in advance
Flexibility to fit our schedule; target a mutually acceptable time.
Same day or next day usually.
This varies; they are usually very accommodating.
If you see the nurse you get in very quickly. However, if you need a clinic appt with the doctor then you can wait longer.
2 weeks later
Quite rapidly
Nurse coordinator satisfactorily looks after making an appointment at first available clinic.
within the same week during scheduled clinic days (generally Tuesdays and Fridays); sometimes on other days if the team is available.
We never had the need.
For clinic appts usually within the hour of registering
Weeks
Quick as possible
Took a couple months (I think) but mainly because of the pregnancy
If it is a ‘clinic day’
Call ahead for an appt and they schedule me in as soon as they can
24. When your comprehensive care clinic is closed or after hours, do you know whom you should contact for help?

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25. When you attend your hospital Emergency Department (ED), are you satisfied with the care you (or your child) receive?

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39 people indicated that their main issue is that ER personnel lack knowledge about bleeding disorders and do not know what to do which prolongs the visits (all comments kept)

13 people indicated that they have not had to visit ER or avoid ER as much as possible. (some comments kept)

Our last ER visit was years ago and we were very satisfied with the care at that time. The best arrangements for most concerns is to be able to go directly to the local pediatrics unit. This is the arrangement we had in previous years, hopefully it can remain in place for hemophilia patients.

We haven’t accessed our ER department in over a year. Prior experiences have really varied-some very negative experiences but also some positive ones.
We don’t visit the ER anymore now that we do home infusions, but it was very frustrating and time consuming at our local hospital. Always had to be admitted and send to PEDS instead of treated in ER
We get very good (although maybe not as knowledgeable) service in emerg. There, we are people and not an inconvenience. The docs are great (know hemophilia) but the nurses don’t always. As a parent, I have to make sure I know the treatment plan b/c clinic doesn’t communicate quickly with emerg
Only when we mention we are factor 8
Not always, they often do not believe you have a bleeding disorder even if you show your card
I guess is the nature of emergency departments
At times but if it involves possible blood disease issues have received a lot of terrible comments and lack of concern. Really hesitant at times to even mention it. Frustration!
Depends on individuals on duty-their understanding of condition and level of compassion
They lost my blood product
Most emergency personnel do not know about HAE and tend to give me the impression I might be a drug user especially if I bring my product.
Have not had to go to emergency.
Generally
Had a joint bleed and waited 4 hours before getting factor (now we self-infuse)
Emergency depts do not seem to be helpful to people with bleeding disorders. They do not seem to believe the patient or know what to do.
The ED staff do not understand the life of hemophilia, the bleeding, the pain and the damage by waiting for treatment.
However I must spoon feed everything to them as they are not well educated.
Went to local Hospital following dental surgery for addtional Factor IX to stop bleeding
They don’t understand and have tried to kill me a few times doing things they shouldn’t
I have had good experiences and bad. The doctors are great, but most nurses have very little knowledge in ER.
We are always at the front of the line-they are always expecting us when we come in.
In reference to our local hospital: although they always lack knowledge about VWD 2A. They often say-follow up with your hematologist tomorrow.
Children’s Emerg is always good!
Have not needed to attend, but I would be apprehensive. Most likely would drive to Vancouver for hemophilia related care.
Yes, the peds department is great and takes excellent care of our son.
I consider myself to be very well educated on the subject and find ER visits to be a very frustrating experience. Last time we saw SIX Drs before he was given his Factor and two of them told me to give him ibuprofen.
We are fortunate to have the pediatrician work out of the hospital so in emergencies he has met us there and things go more smoothly then.
Lot's of doctors in emergency dept. don't know much about C1Esterase
I went to our General Hospital once, took them 3 hrs to get factor ready. Haven’t been to emergency at our HTC
I should go to our HTC only because other one doesn’t know what to do
My local ED is slow and sometimes unaware of medical condition, they don't listen
Wrist broken-factor was very slow to come so this also delayed my treatment-bureaucracy!
When the ED are informed of my hemophilia problem, they attend right away.
In general, when in for a bleeding issue, it is necessary to insist on communication with our care clinic.
Yes, it helps when I show my Factorfirst card
Very slow at addressing issues, even with Factorfirst card
Not a lot of knowledge about hemophilia especially with regards to infusion
Some times
The info is on wallet card.
Haven't attended yet
They know who to contact.
Local ER doctors and medical staff have very limited hemophilia knowledge, I know more than they, have them contact my clinical team for advice, ALWAYS!
Only takes time to wait
We are most often satisfied. Sometimes on weekends or holidays, the staff available is not familiar with hemophilia B.
Small rural hospital—not much expertise
Though sometimes the nurses forget to tell the hemophilia nurses that we are there.
Extremely long waits
I live out of town up north and the ER does not listen to what my care team says.
Went in for xrays—wait took so long I just left and I live 100 miles from Winnipeg—didn't feel good wasting all that gas and time
But not always adequate.
During emergency care, there needs to be a better awareness of hemophilia and multi-disciplinary communication for emergency situations.
Oui mais le service est tres lent
La plupart ne sait pas c’est quoi Von Willebrand et ne savent pas comment administrer le traitement DDAVP
ED staff not always familiar with bleeding disorders and do not know to contact hemophilia clinic staff unless told by patient.
It is getting better but not all staff is aware of the disease and how to treat it... It takes too long for them to look up the information, order the Wilate, then figure out how to give it.
The Adult Emergency seems to be less aware and it’s a long wait to get treated
We attend emerg outside of Janeway as we live outside St Johns
Twillingate health center is a teaching hospital and don’t know much about hemophilia
We have never had too long to wait. Some ER staff are more knowledgeable than others about hemophilia, but often consult with specialists if in doubt.
We have had some good and horrible experiences. However, the nurses at our clinic are very efficient with contacting ER to check on our visits and complaints
Health Care Centre-Eastern Health—excellent facility and we are provided excellent care!
They are understanding and take good care of me.
It varies—sometimes yes, sometimes no
My local hospital is not well-informed about hemophilia.
Local hospital = bad experiences, some ok
Each time is different—depends on the doctor on duty. We’ve run into a real elitist jackass as well as some of the best ER people (Drs).
Not always
Yes at my HTC. No at all other hospitals
Emergency is so slow and understaffed.
I don't know
There are times when the medical doctor wants to do other procedures before giving me the factor.
Yes to the HTC's hospital's ED, no to our local ED as wait times are long even with a child with a bleeding disorder. I'd feel more comfortable with the SBDP hospital.
Good care but long wait time
I feel that rural hospitals do not have enough information regarding bleeding disorders or the implications of a severe joint injury...and because of that I will transport my child to Saskatoon when the need arises.
Some ER doctors are unfamiliar with von Willebrand disorder.
See question #2. Everything went OK. I was surprised the emergency doctor had never used the blood product.
But small hospital (remote community name removed). Do not see patients like me very often so myself or my hematologist do some education.

It took a long time for them to get the meds.
I have never been in for a bleeding related problem but I have had various experiences with them -some good, some sub-par
Very good care but hemophilia sometimes must be explained to staff
They are definitely becoming more educated, but a work in progress-an excellent improvement from the past
Can only talk over the phone for hematology on call. Never looks at situation.
However a very long wait time
Did not often need to request this type of service
ED at a different, closer hospital. See comment under Q3 about wallet cards.
They have no idea about the bleeding condition
Very slow to be processed with knowledge level inconsistet with failure to fully understand this issue and process.
haven't had this situation in a few years - however when I did in the past, as soon as the HTC staff knew I was there, they kicked in to help immediately.
A call must be made to our emergency department - they do not know how to make Immunine - I am alergic to Benefix. HTC hematologist calls our always contact HTC because local hospital not knowledgeable.
The emergency department at local hospital does not provide proper care.
It has been a while since I have had a ED visit but the last few times was a pretty bad experience. I would say due to lack of knowledge but after speaking to the clinic, they were much beter and treatment came faster.
Have needed to advocate from time to time.
I have not attended the ED lately, a few years, but I feel the ED did not meet up to proper standards. I think things have been adressed since.
Although, in Hamilton, there is some uncertainty as to be best ER to visit for an adult hemophiliac. Juravinski or Hamilton General?
Wait times are horrible.
The emerg dept has instructions on what to do right in the dept.
After I call the nurse
Yes, before my hematologist retired, Now-no, sent out to main waiting room with tiny basin-stomach problems, obstructed bowel, vomiting
Or to my previous physician-they think the blood clinic "overrates themselves" and our small town hospital can make independent decisions. It worries me when comments reveal the lack of education in managing our problem.
Very slow, long wait times
Our local General Hospital is uneducated with bleeding disorders ie von Willebrand
Not always: most doctors have little knowledge of hemophilia and when to give the factor needed.
We live out of town so this is a different hospital than Sick Kids.
Home infusion. Have not had to visit our local ER but would likely go to Sick Kids if we did
If I go to sick kids yes, regular ERs don’t know much about VWD
Most of the time
ER is not consistent. On staff physicians need to listen more to parents and empathize
ED is great at my HTC. The ED at our local Hospitals have improved, but not to our HTC’s standards. I work downtown so our HTC is not usually hard to get to.
They don’t always know what to do, they don’t know how to administer meds, not fully aware of humate, etc
Often the hematologist on call is unsure how to handle the situation
Doctors usually insist on providing the wrong factor
My wife is a nurse
Not usually qualified to deal with bleeding disorders

28. Have you ever made a complaint about your clinic?

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answered question 341
skipped question 6
29. Was the complaint process made clear to you?

Answer Options

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At Children’s hospital the doctors make my son feel like everything is his medical life is false inferred, that he doesn’t want to go. They should stick to their field-hemophilia. Or I would have made complaint just about emergency visits.

30. Was your complaint handled to your satisfaction?

Answer Options

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Son was administered Feiba too fast, he had a severe reaction. I sent complaint to the MSW leader, Patient Relations Providence Health Care and Patient Care Quality Review Board. Has not received a final reply. Je ne sais pas- Plainte verbale à la secrétaire et infirmière. Complaint sent to Board of Phy/Surg. No surprise it was brushed aside with no option to appeal. What the dr. did was illegal.

26. What do you think is very good about your comprehensive care clinic?

Comments
The vast majority, over 89 of the respondents, indicated that it is the staff team which they think makes their clinic very good. Most indicated that they find them to be very caring, kind, knowledgeable, personable, understanding, sensitive, empathetic, reassuring, friendly, courteous, helpful and committed. Continuity-minimal turnover of staff was also mentioned.

The quality of the care and service was also rated very highly by a vast majority underlining efficiency, competency, compassion, dedication and professionalism. Services were said to be well organized and meticulous. Many feel they have established trusting, strong and long term relationships with their clinic team members particularly with the nurse coordinators. They feel they are treated with respect.

Many respondents find the clinic staff very accessible, accommodating, attentive, thorough, informative and centered on their needs both as a patient but as a human being as well. More like a family feeling.

Having a multi-disciplinary team to deal with which has many different experiences and expertise was also deemed to be very good. It gives better access to specialized doctor, less wait time on appts. They work together at troubleshooting problems and finding solutions.

As far as communications go, respondents indicated they appreciate the open communications, being listened to and the ease with which they could communicate with the members of their clinic team. Being very accessible by phone and email when needed and providing answers to questions quickly was also much appreciated as well as follow-ups and the unsolicited occasional phone check-ups to find out how you are doing. Knowing you could reach someone 24/7 was also much appreciated.

Regarding the clinic itself, many expressed that having a comprehensive care clinic for bleeding disorders with the specialized programs and services offered all in one location, including good labs, was a major asset. The coordination of medical personnel into one appointment instead of having to return several times for separate visits was valued. Having one in the city where they live or close by was also appreciated. The fact that some clinics travel and most are good at providing service at a distance was also underlined. They feel they can be seen quickly and efficiently. An HTC provides availability to most medical disciplines and the information it provides to other health care service providers and the coordination of care were seen as very valuable. The patient and their family are well guided regarding the treatment and care of bleeding disorder.

The fact that products are available 24/7 or are sent quickly and the good ordering / pick-up services were all highly appreciated. Up-to-date medical information and educational services were valued by many as well as the research activities that are done. Being able to obtain services in English and French was also identified as a good thing.

27. What do you think is most in need of improvement at your comprehensive care clinic?

Comments
58 people indicated nothing needed to be improved or that they were very satisfied with everything.
17 people indicated more personnel including nurses, physicians, social worker and psychologist specifically. Of note, a few mentioned greater access to nurse practitioners.
13 people indicated parking as an area of improvement. Some suggested instituting a special rate for patients and also having the CHS help out patients with a special parking subsidy program.

15 people raised issues about the facilities such as the need for more beds/rooms, a more permanent location for the clinic, larger and more adequate work spaces including better waiting rooms. More and better up-to-date equipment and waiting rooms with toys and other things to keep the children busy and amused. One person mentioned that the signage needs to be improved as clinic is hard to find.

16 people identified long wait times as an issue and suggested that scheduling appointments needs to be improved to make better use of time both for the clinic and for the patients: less wait time between meeting with clinic members. More flexibility with appointments was also suggested. Be punctual and stick to schedule.

4 people indicated that week-end and after hours coverage should be in place.

10 people indicated issues related to the fact that they live far from the clinic which involves long travel times and expenses. Some would like to see clinics closer to home or more outreach type clinic activities/services or their local ED better trained.

Thorough training is important for all clinic staff. We have been disappointed with some of the lack of knowledge displayed by some clinic team members including the current nurse coordinator. The nurse coordinator spoke rudely to our son at a visit to clinic in 2012. Patients and families should be treated with dignity and respect at all times by staff. We have expressed our concerns to the clinic directly. This past summer, we expressed our suggestions for a more open friendly layout of the clinic, which would be conducive to a more welcoming atmosphere and a more positive experience for patients and families. We have in the past had to remind clinic staff that fingers and toes are joints and are also subject to bleeds & that bleeds can occur anywhere in the body; we also had to point out at one visit that a bleed in a hand needs prompt treatment.

The clarity of information given & being more specific. Some information isn't very forthcoming unless you ask & probe. Procedures are very efficient when the main nurse is available but more difficult to order product when she's not there (which of course one can't always be!)

Most things—we need a FT coordinator, better/easier access to doctors; more compassion and teamwork.

Nothing routine. Would appreciate post-surgical follow-up when things go wrong.

I think the doctor's and nurses would know what they need to improve their clinic more than I do. I'm sure they have suffered cutbacks that need to be addressed.

I guess the government could give them more funds for research. This is a wonderful program for the families affected by these disorders. Should advise how often to be seen.

Better "follow-up" with non-emergency matters such as new medication concerns. Dr's and pharmacists are they the best ones? At times it seems no one wants to address issue due to "not theirs" which leaves patient in limbo with no answers but obvious concerns.

Dr's shouldn't get pregnant—it's a joke! We miss them when they are gone! Really, nothing! I asked my wife and she agreed—so thank you—that is rare!

They should allot me more factor for home infusion so I don't have to make pick ups as often.

The only difficult part is when, over time, the nurses/doctors change. I miss the people who have left or retired and it takes time for the new team to know me and for me to get to know them.
They need to follow up with the parents sooner than later/when doctors leave patients should be notified/feels like we’re falling through the cracks

There is not enough paper
I sense a lack of communication within the support staff. Ordering can be disorganized and they don’t seem to let you know when pickup and ordering guidelines have changed.
Consistency and communication. Have been very frustrated lately when dealing with people over the phone. In the past ordering factor (product) was not a problem.
Product-long walk
Organization and communication. To order product, it takes several calls and emails, wasting time.
I had just had that recent experience with my bleeding disorder, so other than what I have already stated (re: consistency of staff and I’m sure difficulties with that) can’t add anything more
Time to see patients. Need to answer phones. Need to return calls same day. Calls are returned within 2 weeks, if returned at all.
Not enough communication on how my bleed levels are looking. I want to try and get off the infusion and wish they would let me know if I can.
I have not met or heard from a doctor in the rare blood disorder clinic for some time. I am however doing well & have not seen the need to call for an appt. The treatment I am getting works well.
Most of the time I place an order for product and supplies and make arrangements for pickup or delivery-something is missing.
More communication to non-specialists in the medical field
I would like to be contacted once per year.
Any equipment (lighting, etc) that can make finding little veins easier.
Chilliwack clinic
Better email communication and perhaps getting an emailed summary of what was covered during the appointment.
I don’t believe I could ask for more. I wish we had access to more psychosocial services but I believe this is a provincial problem, not clinic related.

Finding a social worker who will stay (I don’t know why they leave the position after such a short time) and a psychologist to consult.
Yearly check up scheduling at hours other than 8am. Afternoon for example or 3-6pm.
a dental clinic
Varied factor order pickups at other locations.
Clinic is good. I need a process of availability of Factor IX that is fast in an emergency in my remote location. Ambulance supplied.
Training for my nurse - I feel shame, guilt and fear after dealing with her.
Staying in touch with out of region or not regular patients
Need better communication with doctors and surgical teams who may be treating patients with hemophilia. The advice given to them is to easily ignored or given lip service only.
The range of services that we can receive is not clear to me and there isn’t any guidebook or something like that to provide patients with these information.
Talking with patients respectfully. Don’t mock them. Don’t matter where are they from, know English, know their rights or not...need to people who are sick relate respectful.
Maybe some education for GPs-when I lived in a small & remote town, the GP refused to believe that women could be symptomatic. 
Need to understand different "needs" for different age groups or demographics, and users of the service. We may need it (the service) differently. It would be nice to be able to sort one from another as required.
Better communication with outer lying communities.
Doctors could work faster when seeing patients.
Information and being informed.
More inter-disciplinary communication and cooperation in emergency situations.
Time management
a dentist on hand.
No renewal of Factor 1st cards now that I see that's an expectation on this form.
Not much really. Some signs in the elevator would be great. We now know where to go but it is confusing for new parents/families.
The services offered through the Emergency Department are hit or miss. Some nurses do not know how to mix the factor and have had extreme difficulty administering it leaving our child severely bruised and emotionally drained and very scared.
Greater access to and better communication with other specialists, specifically ob-gyns
Sometimes non-urgent matters are not followed up in a timely manner-they are generally very cooperative so may be due to staffing issues.
These services don't seem to be available to adult patients-I haven't been contacted for a clinic since ending with pediatric care
More resources to take to schools
Educate more ER people on bleeding disorders, etc.
At times difficult to reach nurse for contact and questions in the beginning. Improvements since diagnosis.
Soon we will need regular access to ped.gyn. and would prefer she come to us at clinic rather than go to her wing and wait even longer
The doctor can be quite condescending and/or pushy when it comes to choices our family makes and she does not agree with, our last incident was almost harassing. Will be phoning the manager after the last clinic
I've only met the CHS rep once before. Would be nice to see around more often to be better knowledged on what CHS has to offer.
when I go for blood work they never seem to find my requisition from the Dr (I always have to wait)
For me it is quite good. One thing we have agreed on mutually is to attend Regional Hospital Lab instead of (remote community) Hospital for blood work because we get more accurate test results.
Education in home infusion techniques for other members of family would be beneficial. Also, an order form for supply of factor concentrates and supply of infusion equipment (pdf or on-line) would be helpful/useful.
More specific for adults in dealing with an aging patient.
Some patients, as they age, may actually require more care.
Hospital focus is pediatrics; may consider expanding to adult - outside the control of the clinic - Ministry health issue.
Perhaps greater accessibility to orthopedic surgeon? I know the wait time to be seen by a surgeon is considerable.
To be careful not to lose track of the patients who are on meds prescribed when lose specialists in the program as small town GP not up on the management (and didn't want to be) and bleeding management was lost while waiting for a new specialist-need a plan to avoid this
More qualified physiotherapist for aging hemophilia patients that can better identify the patients limitation.
Must be kept going within hematology.
Making sure the hematologist on call are knowledgeable about hemophilia and administering treatment.
 offering after school appts
 Issues with individual child ie excess nose bleeds and solutions like cauterizing it or kids with allergies and ill effects of bleeding
 Consistency in info from one hematologist to another.
 Sometimes treatment plans are vague and I'm not always sure when/what to do regarding care. It's getting better but for example I don't even know when my next annual is.
 Develop a better rapport with patients even if appointments are less frequent
 Have a yearly follow-up program
 24/7 fast track appts should be available at outpatient lab, xray dept and emerg, wait times should be minimal-consider fee?
 How about move to electronic appointment rebooking and changes rather than play phone tag
 Quicker response to phone messages
 IV team to help with my blood work since I do the injections every week. It'd be nice to have someone inject it for me for once. Also it'd be nice to have someone to look up to me rather than look down (nurse specific).
 31. What other comments would you like to make?

Comments

In late December the nurse coordinator was extremely rude to me on the phone when I called to request factor. The nurse coordinator did not seem to realize that factor dosages are calculated acc to weight and insisted that my son's 30iu/kg prophylaxis dose should be the same iu's that it was over 2 years ago. The realization finally seemed to dawn on this nurse that dosage needs to change as a child grows and gains weight. But I was disappointed by her rudeness & also concerned that other families esp those new to hemophilia not be getting correct advice.

In all the years we've been with this clinic, I have never felt like we were co-partners in our son's health. It has always felt like them controlling the situation & I have no right to questions or disagree. We have asked to be moved to the adult clinic but were denied as our son is still quite young. We have even considered moving just to have a different team, as we don't feel we're on a team. I'd prefer to stop going to clinic altogether if we could. Thank you for allowing me to voice close to 10 years of feelings that I otherwise wouldn't feel free to share.

Again, I cannot say enough about the care I was given. RN, receptionist, Dr were all amazing. I thank your whole society. I hope some studies are done.
 parking is expensive
 Our HTC has the clinic stuffed into an awkward spot. They could use a nice space where their offices (another floor), treatment area and clinic (another bldg.) were all together.
 The care that I receive is excellent!
I am glad that we have this service. Since my diagnosis I’ve been taken care of and after the diagnosis of my child, the same. They look after our issues and make sure we are healthy and also they look after our well being emotionally. 

My hematologist (& son’s) prior to July ’11 told me I did not respond to DDAVP (after testing it) This clinic has this as #1 thing for me-in surgery and next 2 days had gained 15lbs while NPO-very uncomfortable for no gain. Also meds Rx’d (by distance) made me nauseated and were given between meals which were unedible hence nausea and vomiting (colectomy).

How do I know if I need a wristband
I am very impressed with my clinic and the doctors and nurses who work there. They have been a great support to me and I have received treatment (surgery) that has drastically improved my monthly bleeding problems. 

My bleeding disorder is called functional platelet disorder.
Stick to hemophilia and don’t contradict Doctors especially if the child has a special bond with them for many years. This has only happened at Children’s.

Very good clinic
I am very grateful to have been referred to the clinic. Review/follow-up 100% improvement from many years ago of initial diagnosis. Nothing was really in place then. Always treated well when attending clinic. Keep it up! Also 3 1/2 hrs away, not always that close just to pop in when required.

I am very grateful to my Dr. for referring me to this clinic. If nothing else it has given me some peace/relief to know (think?) there are those who care about me and are looking out for me. Attitude makes a big difference & I have seen the other side :(.

My HTCis wonderful. Staff-doctors-nurses always available.
My 2nd cousin has a 1 yr old son with hemophilia also. They lived in the Yukon and I tried to suggest to them to move over here in my town. That is how much I trust the clinic here. Just an idea: Also, I was thinking if every hemophiliac wrote the top 5-10 best advice, then compile it into a book for families new to hemophilia, it would really help those like my cousin :) 

All the girls at the clinic I go to are friendly, kind and considerate. They make sure I am well taken care of no matter the situation. Trips, surgery or dental I can be sure they are on top of things.

Our daughter sees many different clinics & we don’t have any other issues with follow-up besides the hematology. They don’t seem to have a good system in place. We are never forgotten about with any other clinic. When someone says they are going to follow-up, they should.

The one and only time I attended this clinic was due to requiring surgery.
I would like to have online access to my blood test results.
I took blood product for over 2 years when nothing was wrong at much expense to you and me not to mention danger, etc
I have only been diagnosed within the last 18 months and I would really find it helpful (reassuring) to know if my experiences are "normal"! I find the clinic nurse very noncommittal on my questions.
Without or before I was put on Berinert, life was very difficult. Thank you for doing the research so I can live a great life. I’m very interested in the research for the synthetic product for HAE.

I appreciate having clinic but it’s become a time consuming task when trying to speak with someone. There needs to be a better system in place to order product (online?) as well as a more efficient system for logging product use, Prophylactic treatment should be quick and easy to log.

comprehensive clinic is vital to those of us on home infusion and also to navigate ER departments and admissions
We have had issues with the constant turnover of nurses, that is the reason we got a port so we did not have to deal with the inconsistent care. Our son is a pediatric patient.

Very grateful that we have this clinic and this staff—which 30 yrs ago when I accessed the system with my son with hemophilia seems improved. And thank you for sending this questionnaire which has given me more information.

Needed assistance with employer/too many attacks—employer causing attacks—wanted letter for EI—quit job—called clinic—would not do for me. Feel like a number—no support for daily living with disease—disappointed!! frustrated!!

Very well put together program!

I think, what I can see the clinic is ok. If it's not broken, why fix it—leave it alone.

Very understaffed. Still waiting on results for another child. He was seen Jan 28 in lab—today is April 1—unacceptable wait times.

The process required (diary) is very time consuming. I give my subQ the same time 1 location every day. Nothing is ever different—I should only have to record abnormalities.

I do not attend any clinics. When ill I see my physician—a super doctor.

This sure was hard to fill out. I get infusions of IGG by IV every 5 weeks due to a hereditary immune deficiency. The service in my HTC is first class & the nurses are great. I do not have a bleeding disorder per se. I have a blood disorder.

Hope to see you soon at next appt—when?

Could the instructions for formulating Factor IX (dilution?) be improved? The hospital nurses on one occasion took an inordinately long time (2hrs) before figuring it out

The nurse I deal with the most, and the other frontline staff are always very professional, helpful and friendly!

This questionnaire doesn’t seem to apply to me. I have an angioedema like condition which flares up periodically and to date is undiagnosed and untreated. I see a specialist approximately every 2 years, give blood samples for research study. I do not need ongoing access and am quite satisfied to date with my contacts.

Teach the nurses and doctors at the hospitals how to treat VWD patients—too often the disorder is minimized or treated like its is not a big deal. I can't tell you how many times I’ve been told "I don't need DDAVP (before surgery even!) or I am able to take ASA products."

Why don't I see a doctor at the clinic regarding my health issue?

Very grateful for the care we receive for our son

Would be nice if more hospitals dealt with bleeding disorders.

We feel very fortunate to have this superior level of support.

Thank you all for being there for our son and for the sensational work you do for all the children and their families.

My son was born in the US and treated at multiple US hospitals. Upon moving to Canada, I was concerned about his specialty needs. I now have complete confidence in our clinic and feel very comfortable with his care.

We hope that they continue to serve the northern half of the province with outreach clinics—something new that they have just started offering.

The only comment I would mention is how challenging our journey has been because we are located in a rural isolated community. Lack of understanding regarding the limited services at our small hospital (ie access to IV teams for our babies; MRI access) is something we are trying to overcome.
I would like to nominate our nurse for an award. She and her colleague are amazing, but our nurse has been with the clinic longer. She finds time to write articles in Hemophilia Today, often writes letters to assist our chapter with funding, presents at workshops, makes herself available after hours and on weekends, is so easy to talk to, listens well to her patients or their parents/caregivers and knows how to explain difficult concepts easily! She is also genuine and a truly lovely person as well as a dedicated nurse coordinator. Our nurse coordinator also volunteers her time at camp!

Dr. , nurse and the team are the nicest, most caring and fabulous group of people to have. Very smart and very efficient. We greatly appreciate the efforts, professionalism and dedication of all clinic members/staff.

I was seen once on moving to BC from Alberta in 2012. The Dr whom I saw, did an evaluation and decided I'm not abnormal. I do not have a bleeding disorder diagnosis. Sorry this isn't filled out fully because of the lack of time spent with the CHS.

Great work! The team at our HTC are a prime example of how hemophilia care should be around the world.

don't change the staff-regular, familiar faces make us patients feel at ease

I am happy with the help that I am given even though it is rarely that I need it.

As stated above-easier access in my city

Good, steady, seasoned group of hemophilia clinic professionals. They know their stuff.

The clinic and staff are very helpful and fill all my needs. I never hesitate to ask a question and always get an answer from all staff. I feel safe that they know what they are doing. The clinic is very important to me and my health.

My grandson is a hemophiliac (2 years old) in a remote location. he goes to Children's Hospital and in future he could definitely use Factor IX but it is not here. We need to improve this deficiency.

Our HTC Program nurse needs sensitivity training and should not call patients at home in a harassing manner. I am afraid for my son's healthcare if I say anything.

I've only been involved with clinic for one year but so far the care has been excellent! Patients first-

Thank you for the opportunity.

Excellent program/excellent staff/excellent delivery of care

It will be good if there are two or more parking spots available for patients attending the program/clinic.

The people at our HTC are very professional and caring. I see a Dr. my remote town once a year and he does blood work for me. I believe he keeps in touch with my HTC.

I hope my complaint will help that other people don't will have similar problems since I had.

So impressed by the clinic team. Made me want to go to med school :)

Thankful for what I get and have...thank you CHS, thank you doctors and staff, a big thank you for those who have retired but whose kindness/service are always remembered!

My HTC team should be recognized for their exceptional care and dedication.

We are satisfied with the bleeding disorder team...

Keep on being great!

I'm so satisfied and very happy, blessed to have the whole team and all the doctors helping my son with his health issues—may God bless them always.

Our nurses at clinic have been a lifeline through some difficult times. We really appreciate their empathy and knowledge.
I think we have a really great hemophilia team! Keep up the good work. Where would we be without you?
Add trained nurse to administer FS products, IV lines after or during surgery in all hospitals in our city. Full dental coverage to hemophilia patients and funding for alternative medicine $2000 per year would help.

I am a VIII Von Willebrand’s bleeding disorder and sometimes they don’t treat me like a bleeder.
I would like to say thank you for all the effort that has been put into this hemophilia care but especially my thanks go out to our nurse coordinator for all she has done for these children. This woman has been like an angel to my child.
In a recent injury, I was treated too conservatively by the ER physician who was not knowledgeable enough with hemophilia. This resulted in multiple ER visits and plastic surgery, to deal with infection and close the wound, which had not been stitched in the first place. Better communication between wound care, plastic surgery and the hemophilia clinic team would have resulted in fewer re-visits, no need for plastic surgery and cost savings in the long run. This would have resulted in a shorter healing time with less missed work and a better wound management outcome.

Excellent clinic with excellent staff! They do very good and are always there when you need them or want a question answered.
Merci à toute l’équipe.
Aucun commentaire—je suis satisfaite chaque fois que je vais au rendez-vous.

We are very pleased with the clinic and how our nurse makes sure we are updated with anything new from the CHS that may impact our family regarding treatments and studies on VWD.
Because of travel distance, any questions are done by phone. Always get a prompt reply. Dr & nurse take the time to know you personally as well as your medical information.

Thank God for the clinic and the Canadian Hemophilia Society.
Very professional and competent. Provide telephone info/directions when needed (i.e. prior to colonoscopy or any dental work).

I fear that due to budget cuts in the hospital hemophilia care will suffer. Clinic hours have already been cut and several days of the week; my care is managed by a clinic 100 miles away. Clearly a poor way to care for a hemophiliac having a severe bleed.

More money should be made available to hemophilia nurses to help out hemophiliacs when needed and I think patients should have their teeth cleaned every six months for patients who cannot afford it and living on fixed income.

Excellent staff! Great care!
Would love to know what dental care is available in Newfoundland and what is covered what’s free. Thank you. They really are doing a great job!
When I was hospitalized, the hemophilia nurse came to see me every day to check on my treatment because I had a leg amputation and another time heart bypass surgery and they were very concerned about me.

I have been very pleased and grateful for the care my child has experienced. I am glad that we live in close proximity (same city) to the clinic so that accessibility is not a problem.

We are extremely lucky to have the wonderful, caring people we do that take care of our child. They are beautiful people with our child/family’s best interests in the forefront at all times. They are readily available to answer questions and provide services. They are a fabulous team!
Very satisfied with the care received! The issues of concern are outside the realm of the clinic and are the result of lack of govt funding & a long legacy of health care administrators making moronic decisions.

I am pleased that the hemophilia team is in contact with doctors at my local hospital. I am sure that if there were any problems or concerns that the doctors here are aware of our conditions and can properly treat them.

We are very pleased with the patient care and availability of nurse coordinators and doctors @the clinic. We feel they are doing an excellent job and very caring for our son.

I have a great team here. Couldn't ask for any better-and they are only a phone call away.

The people I've been involved with in the clinic are very kind and take good care of me when I'm there. They are a good bunch of people to be around. I'd like to get more detail of what's going on with my Hepatitis C since I haven't had check-up for a while.

I am a mild (female adult) hemophiliac and do not need the services of the clinic on a regular basis-it is usually due to a dental or medical procedure being anticipated or performed-otherwise an emergency.

I feel it would be beneficial for there to be access to an adult clinic in other areas of the province, for people living outside of Eastern Health

I always feel I'm in good hands!
Very reassuring to know we can always speak to someone for advice 24hrs/day.
They have provided us with info on summer camp, medic alert and the society. They monitor his iron thru our family Dr, and stay on top of his general health. I am very pleased with their services.

Please present the statistical analysis of the major questions back to the membership as a national and provincial performance metric/presentation.

It would be good to receive more information on support available to cover the cost of medical supplies for home care. They are very expensive when infusing 3 times a week or more often.

Feel so blessed that we have the HTC to turn to. It is worth the 4hr drive-always feels like we leave knowing great care and knowledge was provided.

Thankfully we haven't had any emergency situations but feel fairly confident it would be well handled.
As an older patient, I do fine looking after myself. Haven't required emergency care. Just keep the access to required (not recommended - never enough) Factor available.

My Dr seems to be judgemental and gives me the impression she is prejudice; I often feel uncomfortable i.e. gestures and attitude after exam is complete.

Some doctors & nurses in emergency not aware of hemophilia problems. Our hospital is a training hospital and the turnover of doctors is very frequent.

We are very blessed to have the team we have. Our care is excellent. Our doctors and the team are wonderful. The only improvement would be more funding so they could cover more hours-we recently did receive more $ and thus the hours HTC is available to patients has been expanded.
Although it has improved, continued Educational Programs for in-hospital staff is necessary.
Only that I am most grateful for the entire team. Whoever I have needed at the time has been there for me. Considering their workload, we are all well looked after in my opinion. A great group on this team.
Value of provincial hemophilia society organization is great. Also the periodic national hemophilia magazine is tops.
The program and regular appointments give me and my family a comfort level in dealing with my bleeding disorder. I feel comfortable in simply calling the clinic if I have a question or concern. Thank you for that!!
At the last check-up I was advised of a support group that may be of interest-when I said I was interested they contacted the group and I joined-THANK YOU.
I feel I'm constantly having to jump through hoops because I've embraced this life and take everything in stride. We've been on home infusion for almost 3 years with no problems and was made to do a "mandatory" review with infusion done in front of a nurse but after talking to another nurse found out that this protocol is for those having difficulties and does not generally include doing another infusion in front of a nurse. I've embraced the life but am made to feel incompetent a lot.
People at my clinic are friendly & helpful. Whenever I do have questions, they are answered in a timely fashion.
I live in between two clinics located in two different provinces. I have been treated by one clinic before my provincial clinic got a hematologist. Now I am attached to my provincial clinic. I have the advantage of having that other provincial option need be. That is important as I go to the other province several times a year.
My von Willibrands is very mild so I am very fortunate.
Two of my grandsons are severe hemo. Thank goodness they were born in Calgary. They have an excellent hemo clinic there at the Children's Hospital. My daughter and her husband would like to move back home however our HTC in this province in our opinion is not adequate to take proper care of the boys and the other provincial one is too far away.
We would like to know what will be needed or what to do as my daughter is approaching her teen years
I am very grateful to my clinic for making a very medically scary time for me bearable. They let me know that I wasn't alone and made themselves available for anything I needed.
Our regional service city has been without a full time hematologist for many years-I think we could benefit from having one.
I love and cherish my primary care nurse and physician. I have been a patient for 20 years and would have absolutely been lost without the support, education and assistance. I am so thrilled to see the growth and outreach every year at the clinic. The education and knowledge that is continually advocated is so encouraging. Keep up the great work! Thank you!
Not sure how to change emergency. Really need help in after hours. Really bad experiences the last couple of times in 2014. Way to long for factor and with no hematology to see you. Wait long time in emergency.
The clinic is very nice. I have nothing to complain.
Our first language is French and we often receive info, surveys, invitations in English which I think we should get either in French or both official languages. Thank you!
I believe the people at our HTC are top rated and do an excellent job for my needs. Keep up the tremendous work and care of your patients. Thank you for all you have done for me in the past 37 years. I have no complaint; sure, I have to wait a while for my appointment but that's the way things are and you just have to adjust to the situation. I can fall asleep in one of those chairs. I am thankful for the help which is offered. My Dr is very nice.
More specific adult care and assistance / training for patient in dealing with issues as we age. I feel very fortunate to have access to the our HTC -- it is a great comfort to me & my family that they are there. As I have aged, I noticed the number of yearly tests have decreased substantially. Appreciate opportunity for being able to give feedback. I have been a patient of this clinic for 30 years - excellent - everyone does their job so well!

Members of my HTC team are all amazing through all our visits. They have treated us with respect, courtesy, and professionalism. Excellent clinic!!

I've had some bad experiences at the my local General Hospital concerning my hemophilia. They are my local hospital and I would be a lot more confident if they were more updated and educated on hemophilia.

I have been going to this clinic for years and I hope I never have to go anywhere else. The staff is always available for consultation and all and all make life easier. I am very thankful to have the team I do.

I've got a great team and awesome support at my HTC. Thank you for making this questionnaire available, and doing what you can to make living with hemophilia easier!

I am happy with all the services and all my needs have always been met. They are very professional and thorough. Thank you for pursuing the identification of and establishment of standards of care and continued research. I have been a patient of my HTC for 40+ years and the care has always been exceptional. Satisfied with everything so far

Excellent
Both physicians along with their team have made me feel "at home" at my HTC. From top to bottom, including the research team, I have nothing but great respect and admiration. Dr. in another HTC was very much the same. He would even call me at home to talk to me. When I moved to the my new area, not only did he find a hematologist for me but he took the time to call me at my new residence to remind me of my appt with my new Dr. Above and beyond the call of duty!

Need a program to include education and co-ordination with GPs for things as simple as iron level monitoring. GPs need to be more informed of bleeding disorders outside of hemophilia-so many pts not yet dx and life could be so much easier, esp for women. My clinic was a godsend.

My health care team have reached across the country to help my family and save my brothers life. They are an amazing team. I feel that if ever I am in need of any care for myself, I am comfortable and confident with my care clinic. I am satisfied with all the services that I need, I know that I would always be in good care. Very good clinic. Excellent staff, especially our nurse. Very satisfied with the services provided.
Give our nurse an award!

Je suis très satisfaite des services obtenus!

Re question 24: don't know who to call after hours but I would call the number and assume/think there is an appropriate message. Area hospitals should have someone knowledgeable about hemophilia and administering treatment, especially on holidays and week-ends. Overall we have had positive experiences with the clinic.

Keep up the great work.
I'm happy to have received this survey and hopefully some points will be taken into consideration as I am aware there will be many. #1-Parent parking fee too expensive #2-Clinic wait time too long
My HTC is a God send inspired care for me for over 21 years. God bless them. My Dr. is the best.
I'm glad as a Canadian that we have these services readily available. Many countries envy what we have and most take it for granted—not me!
The attitude of total concern and care, as expressed by the founding nurse-coordinator has rubbed off on the staff and continues with the current personnel.

I think it's very important to have a women's clinic. Thank you for helping to build this out.
The clinic in my experience has been great. Full access to all necessary expertise in both a regular maintenance capacity and on a more urgent basis when required.
My disorder is very mild, yet had affected my life in a major way. When my son was born, blood work was done. According to the hospital doctor, he did not have hemophilia B.

I am sure from my above responses that I think highly of my clinic and the care that I receive.
Keep up the amazing work, we need more of it.
Not impressed with my Dr. the last visit. He advised me the set of bloodwork indicated I did not have VWD??? Meanwhile, all other past bloodwork, bleeding times, tests and history of post-op bleeding, difficulty healing and easy bruising as well as heavy menstrual cycles were diagnosed as VWD. Didn't appreciate his bedside manner and little information given to me/RN was very pleasant/Wait time was long for no good reason

Move CHS head office to Toronto
My HTC provides an excellent service!
I would like to transfer all medical info to my local hospital.
I have been a patient at my HTC for many years and it has only improved over time. Thank you for taking the fear out of a hereditary condition that could potentially limit lifestyle choices and aspirations.

My hospital and the clinic are great, thank you for having these services. many of us need help
Improvements in access to qualified medical staff outside normal business hours
Stopped going when my nurse retired. Her replacement was not available over the lunch hours which made it inconvenient for me to visit.
My HTC is terrific as is the HTC where I was cared for while attending university.
ANNEX 3: Assessor biographies

Sarah Crymble
Sarah Crymble is currently the Ontario hemophilia provincial coordinator. She began this position in 2007, transitioning from the role of Provincial Program Manager with Hemophilia Ontario that she started in 2003. As the hemophilia provincial coordinator, Sarah’s prime responsibility is to support and sustain Ontario’s Hemophilia Treatment Programs, facilitate sharing of information among them, and help them to maintain the provincial and national standards of care for people with inherited bleeding disorders. Sarah is responsible for managing the Factor Concentrate Redistribution for the province of Ontario. She works closely with the Blood Programs Coordinating Office, Ministry of Health and Long Term Care, and the Canadian Blood Services on matters pertaining to product utilization/distribution and delivery of care.

Michel Long
Michel Long is the national program manager of the Canadian Hemophilia Society. He joined the CHS in 2007 after a long career as a senior manager with both Canada World Youth and the Montreal YMCA. His responsibilities include administration of CHS’ five research programs, staff support of the CHS Research Advisory Committee and the CHS Peer Review Committee, providing support and expertise to CHS’ twinning projects with hemophilia organizations in the Developing World and the CHS International Committee, and operation of CHS programs to support people with bleeding disorders affected by HIV and hepatitis C including staff support of the CHS National HIV-Hepatitis Committee. More recently, he has taken on additional programmatic responsibilities including supporting aging with a bleeding disorder workshops and the present assessment of the Canadian Hemophilia Treatment Centres.

David Page
David Page is currently the national executive director of the Canadian Hemophilia Society (CHS). He served as a volunteer with of the CHS from 1982 to 2001 including a 2-year term as national President from 1992 to 1994. In 2001, he left the field of teaching and educational publishing to take a permanent staff position with the CHS. He was a member of the Canadian Hemophilia Standards Group, which developed the Canadian Comprehensive Care Standards for Hemophilia and Other Inherited Bleeding Disorders.

David served on the Board of Directors of the World Federation of Hemophilia from 2000 to 2008 and has visited Hemophilia Treatment Centres (HTCs) around the world. In 2008, 2011 and 2014, he was the patient representative on the multidisciplinary teams that audited Irish HTCs for the Irish Haemophilia Council.

David has severe hemophilia B (factor IX deficiency).
ANNEX 4: Canadian Comprehensive Care Standards for Hemophilia and Other Inherited Bleeding Disorders
CANADIAN COMPREHENSIVE CARE STANDARDS FOR HEMOPHILIA AND OTHER INHERITED BLEEDING DISORDERS

First Edition
June 2007

Authored by the Canadian Hemophilia Standards Group

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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 Conference. The authors acknowledge a long standing wish for national standards dating from the conference Comprehensive Care for the Canadian Hemophiliac, Winnipeg, May 1978.

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 MEMBERS

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

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3 Proceedings available from the Canadian Hemophilia Society

4 See Appendix for details on individual members
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
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 HTCs 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 CARE

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.

*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 Care**

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.

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6 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).
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.

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

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.

Numbering of Key Indicators refers to the corresponding Standards
STANDARDS - 3. THERAPEUTIC SERVICES

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.

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10 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 AHCDC 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 Services

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.

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


National Hemophilia Foundation, *Comprehensive Care for People with Hemophilia*, 1991


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


The Association of Hemophilia Clinic Directors of Canada. Clinical Practice Guidelines. 1999

Glossary

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

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.

AHCDC: 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

- Congenital Bleeding Disorders: Principles & Practices. 2000 Hemophilia Nursing Alliance (Aventis)

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

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Affiliation</th>
<th>Location</th>
</tr>
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<tbody>
<tr>
<td>Dorothy R. Barnard, MD, FRCPC</td>
<td>Section Head, Immunohematology</td>
<td>Dalhousie University</td>
<td>Halifax, Nova Scotia</td>
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<td>Halifax, Nova Scotia</td>
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<tr>
<td>Mary Jane Steele, PT, BSc</td>
<td>Physiotherapist, Hemophilia Treatment Centre</td>
<td>London Health Sciences Centre</td>
<td>London, Ontario</td>
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<tr>
<td>Morna Brown, RN</td>
<td>Clinical Resource Nurse, Hemophilia Treatment Centre</td>
<td>Alberta Childrens Hospital</td>
<td>Calgary, Alberta</td>
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<tr>
<td>Jerry Teitel, MD, FRCPC</td>
<td>Director, Hemophilia Treatment Centre</td>
<td>St Michaels Hospital</td>
<td>Hamilton, Ontario</td>
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<td>University of Toronto</td>
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<tr>
<td>Maureen Brownlow, MSW, RSW</td>
<td>Social Worker, Hemophilia Treatment Centre</td>
<td>IWK Health Centre</td>
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<td>David Page</td>
<td>Director of Programs and Public Affairs</td>
<td>Canadian Hemophilia Society</td>
<td>Montreal, Quebec</td>
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<tr>
<td>Erica Purves, RN MN NP</td>
<td>Nurse Practitioner, Hemophilia Treatment Centre</td>
<td>BC Children’s Hospital</td>
<td>Vancouver, British Columbia</td>
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<tr>
<td>Julia Sek, RN, BScN, CCW</td>
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<td>Ontario Hemophilia Provincial Coordinator</td>
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<td>Pamela Wilton, RN</td>
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Additional Comments

From the Audience at the CHS/AHCDC 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 HTCs 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.
ANNEX 5: Additional tables

**Table 5: Full-time equivalents (FTEs) per 100 hemophilia A and B patients in pediatric centres**

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<th>Centre</th>
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<tr>
<td><strong>Total</strong></td>
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<td><strong>1.4</strong></td>
<td><strong>1.4</strong></td>
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<td><strong>Mean</strong></td>
<td><strong>1.20</strong></td>
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<td><strong>0.30</strong></td>
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**Table 6: Full-time equivalents (FTEs) per 100 hemophilia A and B patients in adult centres**

<table>
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<th>Centre</th>
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<td>9</td>
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<td><strong>Total</strong></td>
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<td><strong>0.4</strong></td>
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**Table 7: Full-time equivalents (FTEs) per 100 hemophilia A and B patients in the five largest combined adult / pediatric centres**

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Table 8: Full-time equivalents (FTEs) per 100 hemophilia A and B patients in the five medium-sized combined adult / pediatric centres

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Table 9: Full-time equivalents (FTEs) per 100 hemophilia A and B patients in the five smallest combined adult / pediatric centres

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