COMPREHENSIVE CARE STANDARDS SELF-ASSESSMENTS

CONDUCTED BY THE

Canadian bleeding disorder comprehensive care centres

REPORT PREPARED BY THE

Canadian Inherited Bleeding Disorders Standards Working Group

Thank you to the staff in the 26 Canadian bleeding disorder treatment centres who took valuable time to complete the self-assessments and provide the data for this national report.

APRIL 2023

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CANADIAN INHERITED BLEEDING DISORDER STANDARDS WORKING GROUP

The self-assessment of the Canadian Integrated and Comprehensive Care Standards for Inherited Bleeding Disorders[1] by the 26 Canadian bleeding disorder treatment centres and the national report were planned and overseen by the Canadian Inherited Bleeding Disorder Standards Working Group, which included the following members:

Association of Hemophilia Clinic Directors of Canada

- Lawrence Jardine (co-chair), Ontario
- Natasha Pardy, Newfoundland and Labrador

Canadian Association of Nurses in Hemophilia Care

- Karen Sims, British Columbia
- Marie-Hélène Thompson, Québec

Canadian Hemophilia Society

- Kathy Mulder (co-chair), Manitoba
- David Page (writer and project coordinator), Québec
- Bojan Pirnat, British Columbia
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- Wendy Quinn, Saskatchewan
- Pamela Wilton, Ontario

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- JoAnn Nilson, Saskatchewan

Canadian Social Workers in Hemophilia Care

- Jennifer King, Saskatchewan (until 2021)

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- Sarah Crymble, Ontario

EXECUTIVE SUMMARY

The *Canadian Integrated and Comprehensive Care Standards for Inherited Bleeding Disorders* represent the second iteration of standards of care for people with inherited bleeding disorders in Canada and were adopted by four health care provider groups and the patient association in June 2020. They replace the First Edition of the *Canadian Comprehensive Care Standards for Hemophilia and Other Inherited Bleeding Disorders*, published in June 2007. The standards development and the self-assessment process were funded by the Canadian Hemophilia Society.

The self-assessment of each centre's capacity to meet the standards was originally scheduled for 2020 but was delayed by the pandemic and occurred in late 2022 and early 2023. Health care providers in the network of 26 treatment centres were provided with a checklist to allow them to indicate whether or not they were able to adhere to each of the 66 standards of care in the following categories:

- role of treatment centre
- diagnosis
- care
- patient/caregiver education and support
- product monitoring
- human resources for integrated care
- physical resources
- information systems, health records and data collection
- linkages
- accreditation, audit, quality assurance and research.

All 26 centres completed the self-assessments and provided the latest patient and staffing data.

Collectively, centres report meeting 88.8% of the standards. The adherence for each standard ranges from 40% to 100%. Adherence by centre ranges from 48% to 100%. Pediatric centres are marginally better able to adhere to the standards compared to lifespan and adult centres. The number of patients registered in the centre, ranging from 100 to over 1500, appears not to be correlated with adherence.

The data collected and the accompanying comments indicate that the standards are appropriate and attainable; however, staffing shortages are a barrier to adherence for many centres.

Staffing shortages are especially acute in physiotherapy, social work, and data entry and data management. They lead to barriers in adhering to standards in key areas such as:

- psychosocial support
- clinical assessments on an appropriate schedule
- treatment and follow-up of bleeds and rehabilitation
- musculoskeletal assessments
- monitoring of coagulation product usage and education of people with bleeding disorders (PwBD) and their families in reporting bleeds and home treatments
- documenting outcomes and routinely exporting data to provincial and national databases.

Recommendations

1. That these standards be used in any formal audit or accreditation process.
2. That comprehensive care teams review their own self-assessments in comparison to national practices with the goal of identifying remedial actions.
3. That each centre's self-assessment and the national report be shared with the hospital administration, ministry of health and local chapter of the Canadian Hemophilia Society with a view to correcting deficiencies.
4. That each centre consider distributing the patient satisfaction survey, based on these standards, to add the patient voice to these assessments.
5. That the standards be reviewed and updated every five years.

DEVELOPMENT OF THE STANDARDS

The *Canadian Integrated and Comprehensive Care Standards for Inherited Bleeding Disorders* represent the second iteration of standards of care for people with inherited bleeding disorders in Canada. The standards were written by the Canadian Inherited Bleeding Disorder Standards Working Group, which included representatives of the Association of Hemophilia Clinic Directors of Canada, the Canadian Association of Nurses in Hemophilia Care, the Canadian Hemophilia Society, the Canadian Physiotherapists in Hemophilia Care and the Canadian Social Workers in Hemophilia Care. After extensive consultation with members of these associations, and with international standards including the World Federation of Hemophilia Guidelines for the Management of Hemophilia, 3rd Edition[2], the standards were adopted by each group in June 2020.

The First Edition of the *Canadian Comprehensive Care Standards for Hemophilia and Other Inherited Bleeding Disorders* was published in June 2007. It proved invaluable in guiding health care providers in treatment centres, hospital administrators, ministries of health and the patient association in the coordination and delivery of "integrated" or "comprehensive" care for PwBD over the last dozen years.

In 2019, however, it proved necessary to update the standards given the following developments:

- a 272 percent (272%) increase in the number of patients diagnosed and registered in the network of treatment centres from 5,545 in 2004 to more than 15,000 now, largely through increased recognition of abnormal bleeding symptoms and improved diagnosis;
- an increase in co-morbidities due to an ageing patient population, necessitating enhanced collaboration with specialty services such as cardiology, oncology, nephrology, geriatrics and vascular surgery; and an increase in orthopedic interventions) and ongoing evolution;
- the number and complexity of treatment regimens (e.g. extended half-life factor concentrates, non-factor replacement therapies and gene therapy;
- increasing recognition of the need to individualize treatment regimens;
- the introduction of new clinical assessment tools such as point-of-care ultrasound and standardized disease-specific outcome measures;
- the development and adoption of improved tools to monitor and manage care, such as comprehensive registries, expanded pharmacokinetic capabilities, electronic patient files and telemedicine;
- an emphasis on increased participation in physical activities and physical therapy, and preventative medicine;
- increased health system requirements for accountability for utilization of health resources;
- an increasing obligation to collect real-world evidence on health outcomes and an expectation that treatment centres participate in registries such as the Canadian Bleeding Disorders Registry (CBDR) and BC's Inherited Coagulopathy and Hemoglobinopathy Information Portal (iCHIP), and research;
- growing recognition of the impact of bleeding disorders in women, resulting in increased diagnosis, and necessitating improved collaboration with specialties such as gynecology, obstetrics and anesthesiology to coordinate care plans;
- increased recognition of the complexity and impact of mild bleeding disorders;

- increased recognition of the level of pain experienced by many PwBD and the need to manage it;
- increased recognition of the psychosocial issues for PwBD and caregivers related to being diagnosed and living with a chronic condition;
- the introduction in Canada of frequent tendering for the provision of coagulation products and the resulting wholesale treatment product switching for patients every two to three years, imposing on treatment centres the obligation to review, consent and implement new treatments in hundreds of patients;
- an increasing population of new Canadians with bleeding disorders who arrive with joint damage and whose care requires cultural and linguistic sensitivity.

As with the 2007 standards, it was felt necessary to validate the standards through a self-assessment of each centre's capacity to meet them. Originally intended to take place in 2020, the assessment was delayed by the pandemic and ultimately occurred in late 2022 and early 2023 once treatment centre staffing had returned to previous levels and treatment centre practices normalized.

The goal was to validate the standards by assessing acceptability and adherence. As a result, centres can compare their own practices on each standard against those of all centres, identify barriers to adherence to the standards, identify remedial actions and, finally, use the results locally as evidence for needed resources. In turn, members of the health care provider associations and the patient organization can gain knowledge about bleeding disorder care across Canada, be able to highlight national successes, develop new ways to achieve standards, identify limitations in the system and be better equipped to close gaps in care. Finally, the national database would stand as a baseline against which to compare future practices.

The standards development and the self-assessment process were funded by the Canadian Hemophilia Society.

METHODOLOGY

In September 2022, the health care providers in the network of 26 treatment centres were provided with a checklist[3] for assessment of whether they can adhere to each of the 66 standards of care. A score of 1 was accorded for "yes" answers; 0 for "no" answers and 0.5 if the response was both "yes" and "no." The document also allowed for the identification of barriers to meeting standards and implementing remedial actions. Centres were also asked to provide patient numbers for each of the bleeding disorders and the number of full-time equivalent positions (FTEs) in each of the core disciplines. The deadline for submitting assessments was November 30, 2022; however, late submissions were accepted in early 2023.

Centre participation was voluntary but strongly encouraged by the four health care provider associations and the Canadian Hemophilia Society. The responses were anonymized and collated into a single database. Only the project coordinator and three members of the review team had access to the uncoded responses.

Centres were not given instructions on how to conduct their self-assessments. Some checklists were completed by a single individual, possibly after discussions with colleagues. In other centres, a single checklist was completed by multiple members of the care team. In some cases, multiple members of the team each completed and returned a separate checklist, which were then consolidated into a single report and returned to them.

This is the breakdown of the health care professionals who completed the checklist.

Nurse	8
Medical director	2
Nurse and medical director	4
Multiple members of the care team, including nurses, medical directors, physiotherapists, social workers, program managers, administration assistants, data entry managers, pharmacists, research nurses	12

Results by standard

All 26 centres completed the self-assessments and supplied the latest patient numbers and full-time equivalent (FTE) staff positions.

Collectively, centres reported meeting 88.8% of the standards. The adherence to each standard ranged from 40% to 100%. See Table 1. **(See Annex 1 on page 17 for the complete wording of each standard and all the comments submitted.)**

Table 1

REPORTED ADHERENCE	NUMBER OF STANDARDS	STANDARDS	
100%	19	Registering all patients **(A4)** Triage for referrals **(B1)** Imaging capability **(B3)** Guideline-based care **(C1)** Access to services **(C3)** Prophylaxis supplied **(C6)** Coagulation products supplied **(C7)** Ancillary products supplied **(C8)** Respect for privacy **(C15)** Information on diagnosis and treatment options **(D1)** Information on benefits and risks **(D2)**	Information on activities **(D3)** Education on current issues **(D6)** Provision of documents (e.g. *FactorFirst card*) **(D7)** Provision of contact information **(D8)** List of patients on home care **(E1)** Adverse event reporting **(E5)** Day treatment area **(G2)** Maintenance of records **(H1)**
95-99%	3	Transition process **(C14)** Training on infusions/injections **(D5)** Access to reference materials **(F9)**	

REPORTED ADHERENCE	NUMBER OF STANDARDS	STANDARDS	
90-94%	19	Opportunity for continuing education **(A2)** Local awareness of centre **(A3)** Coagulation lab **(B2)** Genetics lab **(B4)** Access to pharmacy and blood bank **(C5)** Access to 24/7 expertise **(C9)** Genetic counselling **(D4)** Support for ageing **(D10)** Links to CBS and H-Q **(E2)** Team knowledge sharing **(F4)** Team collaboration **(F7)**	Facilitation of membership in associations **(F8)** Provision of information to EDs **(I1)** Information to other HCPs **(I3)** Referral process **(I4)** Listing with the CHS & WFH **(I6)** Participation in quality assurance **(J1)** Involvement in research **(J3)** Complaint process **(J4)**
80-89%	12	Sufficient skills **(C2)** Up-to-date policies and procedures **(C4)** Coordination of follow-up **(C10)** Regular clinics **(C11)** Record of education **(C13)** List for extended team **(F5)** Annual treatment plans **(H2)**	Participation in CBDR and iCHIP **(H3)** Regular data exports **(H4)** Recording treatment outcomes in info systems **(H5)** Information to remote EDs **(I2)** Accreditation **(J2)**
70-79%	8	Institutional recognition **(A1)** Recording outcomes **(C12)** Tracking of product use **(E3)** Home infusion/injection records **(E4)** Appropriate staff training **(F2)**	Invitations to meetings for extended team **(F6)** Adequate clinical area **(G1)** Collaboration with CHS chapter **(I5)**
60-69%	2	Full expertise **(A5)** Adequate human and physical resources (quality assurance & research) **(J5)**	
50-59%	1	Process to adjust staffing **(F3)**	
<50%	2	Psychosocial support **(D9)** Full staffing **(F1)**	

Reports of staffing shortages are borne out by the number of full-time equivalent positions (FTEs) for the 26 Canadian treatment centres. See Table 2.

Table 2

DISCIPLINE	RANGE OF FTEs PER CENTRE	TOTAL FTEs FOR CANADA	MEAN FTEs PER CENTRE	NUMBER OF CENTRES WITH NO DEDICATED STAFF (N = 26)
Nursing	0.2 to 4.0	33.6	1.29	0
Physiotherapy	0 to 1.0	6.945	0.27	3
Social work/psychology	0 to 0.5	4.45	0.17	10
Data management administrative	0 to 1.0	8.6	0.33	12

N.B. FTEs cannot be calculated for physicians who perform multiple functions in addition to bleeding disorders such as general and malignant hematology, pediatric oncology, heading coagulation and research labs, thrombosis, internal medicine, etc.

Sixty percent (60%) of centres report being unable to maintain a complete complement of core team members which is adequate to meet these standards (F1). Lack of dedicated staff is particularly apparent in the disciplines of physiotherapy, social work and data management. Even those centres with a full complement report that the number of hours dedicated to bleeding disorders is insufficient.

Fifty percent (50%) of centres report being unable to provide psychosocial support for PwBD and families regarding schooling, employment and relationships, and the provision of social supports and counselling services (D9) due to insufficient human resources in social work and psychology.

Forty-seven percent (47%) of centres report that there is no process in place to evaluate and adjust staffing (F3).

Thirty-seven percent (37%) of centres report not having access to the full range of expertise (standard A5). Centres that identified no staff within a certain discipline dedicated to the care of bleeding disorders indicate they can call on outside resources; however, they often lack important specialized expertise.

Thirty-one percent (31%) of centres report not having adequate physical and human resources to meet these standards with regard to quality assurance and research (J5).

Twenty-nine percent (29%) of centres report not having a clinical area sufficient for diagnosis and treatment that is age-appropriate, comfortable, quiet and adequately equipped, that respects privacy and confidentiality, and that is designed for people with disabilities or mobility aids (G1).

Twenty-seven percent (27%) of centres report that they do not feel supported by their host institution and health authority to achieve the obligations set out in this document (A1).

Twenty-seven percent (27%) of centres do not have a process in place to meet and discuss issues of mutual concern with the Canadian Hemophilia Society and its provincial chapters (I5).

Twenty-five percent (25%) of centres report that they are unable to properly track, monitor and report on home use of coagulation products (E3).

Twenty-four percent (24%) of centres report not collecting detailed health outcomes over time (C12).

Twenty-two percent (22%) report not having a mechanism whereby PwBD and their families record all bleeding episodes and treatments with clotting factor concentrates and non-factor replacement therapies so as to provide the treatment centre essential clinical data (E4). These shortcomings are reported to be largely due to a lack of human resources in data management.

Twenty-two percent (22%) report that the treatment centre is not staffed with core team members who have the appropriate training and qualifications to provide care to the patient population (F2).

Twenty percent (20%) of centres report not having access to staff with sufficient clinical skills to care for all PwBD in a manner that is appropriate to their age and condition (C2). Physical therapy and psychosocial support are cited as key shortcomings.

Eighteen percent (18%) of centres report not being able to keep data current and routinely export data, as required, to the provincial and national databases (H4).

Sixteen percent (16%) of centres do not report detailed information concerning the outcomes of treatment (H5).

Fifteen percent (15%) of centres report not being able to provide regular clinics for all PwBD, including women with bleeding disorders, to permit regular assessments on an appropriate schedule (C11). Regular clinical assessments are considered a foundation of comprehensive care.

Results by centre

The centres reported the following breakdown of registered PwBD. See Table 3.

Table 3

		NUMBER REGISTERED	RANGE PER CENTRE
Hemophilia A	Severe	1,198	1 to 150
	Moderate	342	2 to 49
	Mild	2,118	6 to 312
	Inhibitors	87*	0 to 11
Hemophilia B	Severe	216	0 to 37
	Moderate	249	0 to 48
	Mild	287	1 to 31
	Inhibitors	6*	0 to 3
von Willebrand disease	Type 1	3,527	16 to 621
	Type 2	822	4 to 80
	Type 3	165	0 to 26
Rare factor deficiencies		1,920	0 to 394
Inherited platelet function disorders		1,464	0 to 211
Other (uncharacterized, under investigation, discharged ...)		2,728	0 to 573
Total		15,036	101 to 1,547

* Inhibitors are a sub-set of hemophilia A and B

Adherence to the full set of standards in each centre ranged from 48% to 100%. See table 4.

Table 4

PERCENTAGE OF STANDARDS ADHERED TO	100%	95-99%	90-94%	80-89%	70-79%	<70%
Number of centres	2	6	7	8	2	1

Centres treating only pediatric patients report being better able to meet the standards than adult or lifespan centres. See Table 5.

Table 5

	NUMBER OF CENTRES	MEAN ADHERENCE TO STANDARDS
Pediatric centres	6	93%
Adult centres	6	88%
Lifespan centres	14	86%

There appears to be little correlation between the total number of PwBD registered per centre and their capacity to respect the standards. Large centres as well as smaller ones report staffing shortages resulting in barriers to adherence to the standards. See Table 6.

Table 6

	100-300 PWBD (MINIMUM 101)	301-500 PWBD*	501-750 PWBD	>750 PWBD (MAXIMUM 1547)
Number of centres	7	8	4	7
Mean adherence	93%	81%	90%	92%

* One of these centres reported an adherence of 48%. Excluding this one centre would result in a mean adherence of 85%.

DISCUSSION/CONCLUSIONS

The network of centres report being able to meet the 66 standards with a mean of 88.8%. Nineteen of the standards were met by all 26 centres. Thirteen standards were met by less than eighty percent (80%) of the centres. Only two standards—D9 re psychosocial support and F1 re full staffing—were met by fifty percent (50%) or less of the centres.

Hundreds of comments were received in the self-assessment reports but none indicated that a given standard was irrelevant, unrealistic or unnecessary (with the exception of support for the ageing population in pediatric centres).

These data are strong indicators that the standards, as written, are appropriate; however, staffing shortages constitute a barrier to comprehensive care for many centres.

It came as no surprise to the members of the Standards Working Group, all of whom are very familiar with the provision of comprehensive care for people with bleeding disorders in Canada, that the self-assessments raise alarming deficiencies in staffing levels, notably physiotherapy, psychosocial support, and data entry and data management. The lack of dedicated staff has serious repercussions.

A lack of staff and staffing time results in shortcomings in teams sharing knowledge to promote best patient outcomes. This can be a serious impediment to integrated and comprehensive care.

Staffing shortages are a barrier to the provision of regular clinical assessments with the comprehensive care team on the schedule that is prescribed in the World Federation of Hemophilia Guidelines for the Management of Hemophilia.

Physiotherapy is a key component of comprehensive care. Many PwBD live with chronic musculoskeletal damage caused by a lifetime of joint and muscle bleeding, resulting in functional impairment and pain. In a properly functioning centre, physical therapists not only evaluate and follow up active bleeds but they also manage rehabilitation after injury or surgery, educate PwBD regarding prevention of bleeds and guide them in the choice of sports and fitness activities. The absence of a dedicated physical therapist and insufficient dedicated time mean that many of these functions are deferred. There is insufficient time to complete the Hemophilia Joint Health Score[4] and other musculoskeletal assessments. The lack of a dedicated physiotherapist and/or sufficient FTE for PwBD result in a breakdown of care and attention to joint health, physical activity and overall well-being. Despite improvements in coagulation therapies and treatment of bleeding disorders, this inadequacy will result in ongoing increased demand for hemostasis products, pain management, joint surgeries and replacements, and hospital admissions, along with reduced cardiovascular health outcomes, lost productivity and poor quality of life. Limiting access to physical therapists is counter-productive; it can result in not only poorer health outcomes but also increased costs to the health care system.

Lack of access to psychosocial support in many bleeding disorder treatment centres was identified as a shortcoming following the analysis of the First Edition of the standards. A significant number of PwBD are living with the psychosocial consequences of contamination of the blood system with HIV and hepatitis C in the 1980s as well as their underlying bleeding disorder. The pandemic has only made the situation worse through the loss of trained staff to other areas in the health system at a time when psychosocial issues in chronic conditions such as bleeding disorders are exacerbated. Meanwhile, a major focus of the Canada Health Transfer is access to mental health services. Ten centres have no access to dedicated social workers with expertise in bleeding disorders; many others have resources sufficient only for emergencies. The nursing and medical staff attempt to support patients dealing with psychosocial issues; however, this is not within their scope of practice, detracts from their primary responsibilities and is not sufficient to replace certified social workers.

Twelve centres have no staff for data entry/management. Where these positions exist, available time is lacking. Patient records need to be tracked in the hospital electronic record as well as in CBDR/iCHIP. The result is that the nursing staff are asked to take time away from their duties to do these tasks. Inevitably, acute patient care takes priority; data entry and data management suffer. The monitoring of the home use of coagulation products is delayed or left unanalyzed, which hinders needed adjustments to treatment regimens. PwBD/families are not well-educated in record-keeping with CBDR or iCHIP of products infused/injected at home. It should be unacceptable that coagulation products, costing several hundred million dollars annually to the health care system, are not optimally accounted for and utilized. The collection of national data on health outcomes, essential for advancing comprehensive care for all, is delayed and/or incomplete.

RECOMMENDATIONS

1. That these standards be used in any formal audit or accreditation process.
2. That comprehensive care teams review their own self-assessments in comparison to national practices with the goal of identifying remedial actions.
3. That each centre's self-assessment and the national report be shared with the hospital administration, ministry of health and local chapter of the Canadian Hemophilia Society with a view to correcting deficiencies.
4. That each centre consider distributing the patient satisfaction survey, based on these standards, to add the patient voice to these assessments.
5. That the standards be reviewed and updated every five years.

CENTRES' SELF-ASSESSMENT SCORES, COMMENTS AND REMEDIAL ACTIONS ORGANIZED BY STANDARD

A: ROLE OF TREATMENT CENTRES

A1: The treatment centre shall be supported by the host institution and health authority to achieve the obligations set out in this document, and together with health administration maintain/pursue support and recognition by the provincial Ministry of Health.

19/26
73%

Unsure if official legal status.

Equitable funding model to sustain the BDP program.

Missing full time nursing, data/admin support, social work.

Staffing shortage is an issue. We would need another hematologist and 0.5 FTE nurse to be able to respond to all obligations.

Limited recognition as a provincial program as we fall under a regional health authority. The program is supported by the pediatric centre; although 3/4 of the population served is >age 18. There is limited recognition from the adult health care centre.

Unable to achieve obligations set out in the document; zero funding for social work position and under resourced in nursing.

No funding for social worker or physiotherapist. We also require additional nursing and data admin due to our growing patient numbers.

Need support from management and administrators of the institution.

A2: The treatment centre shall be affiliated with a health care institution and all core team members are encouraged to engage in relevant continuing education opportunities.

24/26
92%

Out-of-province travel requires high-level approval; attendance to meetings may not be granted to more than one team member; education hours for program staff are seen as above and beyond routine SHA education events; ACTION: ongoing conversation with leadership to maximize in-person attendance.

We are encouraged to engage in continuing education but it's often met with resistance when it requires time off. Education in the community is a big part of the nursing role, and this has become challenging in recent years as many health care members are unable to attend due to staffing issues. In our facility nursing is often tasked with administrative duties, therefore it's difficult to get out to the community and raise awareness as needed. Again, nursing strives to register all PwBD and meet the standards; however, it is difficult with the lack of resources.

I do not think all core team member are encouraged by their superiors to engage in relevant continuing education opportunities. Superiors will often "say" they encourage us, but only allow 3 education days/year and expect the member to take his/her vacation time for travel days. Nurses are tired. They don't want to use their vacation to attend conferences. We already have very little vacation approved!!!

HTCs do not have the ability to send a different nurse to each conference and have them present to the others upon their return like they do on nursing floors.

I'm not sure what the remedial action would be? To present and discuss the issue with the health authority and the government or even AHCDC to get support for our center.

Better understanding of upper management and health authorities of the critical work that we do. They need to stop micromanaging our requests and let us do our jobs. They need to be educated.

Due to staffing issues, only physicians are free to engage in CME. We do encourage all members to do so and our members are interested but the administration will often interfere and not allow CME days. Our clinic is growing in terms of patients but we do not have additional resources to meet the demands.

Unfortunately, I have not been able to participate in bleeding disorder conferences and training in the recent years. I will attempt to improve this but will not be able to travel for conferences due to family responsabilities. Can only do virtual recordings viewing during the weekday.

A3: The treatment centre shall raise awareness in the local medical community to facilitate referrals and collaborate in care.

24/26
92%

No comments.

A4: The treatment centre shall strive to register and provide care to all PwBD and their families in its respective region.

26/26
100%

No comments.

A5: The treatment centre shall provide and/or facilitate access to the full range of expertise required to respond to the complex and diverse needs of PwBD, and to meet these standards. (See Appendix 2, Team members and roles: Core and extended.)

16.5/26
63%

No dedicated SW but we do have access to refer to a SW and it is episodic. May or may not be the same practitioner. Continue to adovcate for dedicated SW.

Currently we do not have a physiotherapist for the bleeding disorder program. There is a designated SW in both the pediatric and adult program; however, the % of FTE is very low. Given the high demand for service in SWs main service coverage area, they are becoming increasingly less available to attend clinics and have also been re-deployed for months at a time on more than one occasion.

Continue to recruit for physiotherapist. Requires advocacy to our provincial government to ensure adequate staffing/care. Without adequate core members, efforts for awareness in our community would not be feasible. To reinvigorate institutional efforts to participate actively with the BDP.

We are lacking a social worker on our team as well as nursing coverage when the full time clinic nurse is away.

Difficult access to social workers, very limited access to psychological services. These services are more readily available on the pediatric side than the adult side.

Some patients have to be referred to an outside agency to have access to these services and to compensate for the lack of resources in the hospital environment (for example, at the community health centre). We are limited by the resources and mandates of social workers and psychologists in the hospital setting. We are considering the use of a private fund to pay a social worker.

Note that there are physiotherapists in pediatrics but not for adults.

Missing a social worker.

We have access to this expertise; however, limited dedicated hours: e.g. PT & SW serve many areas, bleeding disorders is 0.2 of each of their positions, and this 0.2 is for the entire pediatric & adult population served by our clinic. Our regional health authorities (HA) will be amalgamating into one provincial HA in 2023. We are hopeful with this move there will be more support for us as a provincial program serving patients in all areas of the province. We do feel we have come a long way since the last set of standards, as we now have FT funding for an NP, RN coordinator and secretarial support. We are lacking in terms of sufficient access to PT and SW, and a dedicated space.

Lacking: in-house dental, genetic counselling, need full time physio and at least 3 x per week SW.

Remedial: need further support from Province and Health Authority for increased FTE as our program gets larger.

Lacking: social worker/psychologist.

Missing social worker, admin assistant, data manager, nursing only 3 days a week.

Lacking: physiotherapist and social worker.

Little access to social work and no FTE of physio. We have physios who are available but not assigned to our clinic.

We can certainly refer our patients to other expertise when needed i.e. GYN, physio, ENT. However, we do not have dedicated members of these deciplines in our clinic.

B: DIAGNOSIS

B1: The treatment centre shall have a triage process for new patient referrals.

26/26
100%

No comments.

B2: The treatment centre shall have access to an accredited hemostasis laboratory with appropriate arrangements in place for 24/7 coagulation testing and establish formal links for specialized hemostasis testing when required. (See Appendix 6, Coagulation testing.)

24/26
92%

Although access exists, processes are not formalized and could be optimized (discussion underway).

Increased turnaround time for results due to lack of laboratory staff.

We do have access to 24/7 laboratory services; however, some of our testing does require samples to be sent out which causes a delay of a least 2 hrs in getting results.

24/7 coagulation testing is "available" upon request only. There could be improved efficiency with lab for highlighting lab work that is required urgent vs usual turnaround time. Complete provincial access to labs related to our patient population would be an asset.

24/7 basic coagulation assays (INR, aPTT), factor assays typically have >24-48h turnaround, unless approved by coagulation lab (around time of surgeries).

B3: The treatment centre shall have access to a diagnostic imaging department and establish formal links where specialized radiology services are required.

26/26
100%

(Nearby city) processes could be clearer (especially joint u/s); ACTION: create reference list of clinics to contact for specific imaging services.

B4: The treatment centre shall have a formal relationship with a genetic laboratory so that all patients and families have access to carrier testing and genetic services.

24/26
92%

We do have a genetics lab we use, but no formal genetic services.

We send genetic tests to the available laboratory. I'm not sure if we need to have a formal associated lab.

C: CARE

C1: The treatment centre shall provide care and treatment based on the most current clinical treatment guidelines. Where guidelines are not available, care shall be based on the most current scientific literature and best practices.

26/26
100%

Compared to other centres, sometimes cautious in offering new products.

C2: The treatment centre shall have access to staff with sufficient clinical skills to care for all PwBD in a manner that is appropriate to their age and condition.

21/26
81%

No dedicated SW.

Lacking physiotherapy.

Physiotherapist does not get the chance to assess active bleeds often (which I guess is good, but then you lose your confidence). I would also say that our secretary who deals with PwBD everyday has never been offered any education on ANY bleeding disorders. One might better understand why we do certain things and their importance if they were provided with some basic information. Not to mention, we only see our social worker once in a blue moon.

No recent training on updated clinical skills specific to bleeding disorders. Would benefit from having a pediatric physio seeing pediatric patients.

Nursing felt that while the answer is yes, this is impacted by time limitations.

Need more staffing hours.

Lacking: social worker.

Lacking: physiotherapist.

C3: The treatment centre shall provide and/or facilitate access to appropriate hematologic, obstetric and gynaecologic services to women with inherited bleeding disorders, including carriers of hemophilia.

26/26
100%

We are able to refer to these services, usually in a timely manner, but do not have a comprehensive multi-disciplinary clinic for women.

C4: The treatment centre shall develop, review and utilize policies and procedures for the treatment of non-urgent, urgent and emergency bleeding episode.

23/26
88%

No formalized policies/procedures, treatment is determined on patient response and follow-up. Assess which would be necessary for program function.

Have PROCESSES, but not always policies, but still accomplishes the main goal.

C5: The treatment centre shall have access to appropriate pharmacy, transfusion medicine and blood bank services.

24/26
92%

We do not have access to a pharmacist.

Lacking formal pharmacy support for PwH. Need improved access to pharmacy services.

C6: The treatment centre shall make prophylaxis and home-based care available to PwBD as appropriate.

26/26
100%

No comments.

C7: The treatment centre shall ensure that PwBD on home-based therapy have access to the required supply of factor concentrates and non-factor replacement therapies.

26/26
100%

No comments.

C8: The treatment centre shall ensure that PwBD have access to infusion/injection equipment and supplies, either by supplying or facilitating procurement.

26/26
100%

No comments.

C9: The treatment centre shall ensure 24/7 access to bleeding disorder expertise to PwBD through the centre, through partnerships, on call or consultative services.

24.5/26
94%

Only MDs on call on weekends and nights.

Adult hematology on-call - inconsistent practices in terms of communication and follow-up needs. ACTION - check status of pre-existing FAQ and update/distribute as necessary.

On call access is not always reliable and is provided by general hematology vs. the Adult Bleeding Disorder Program staff. Clinical consultative sevice is currently being explored. Need on call for the clinic.

C10: The treatment centre shall coordinate treatment and follow-up for acute bleeds, including guidance regarding safe return to activities.

22/26
85%

We would like to be able to see our patients with acute bleeds in follow-up but often do not have clinic time for this and only do a phone follow-up by the nurse. We are not able to see our patients in follow-up as often as we would like or need to because of staffing shortage.

Our HTC does a very good job at coordinating treatments and we do follow up with the patients (mostly phone calls). I think local patients are better followed. Often, patients who live a little further away are treated but left to assess themselves on whether the bleed is better, resolved and ok to resume daily activities. Patients don't always live close to clinic; therefore, are monitored via phone calls.

Could use more physio assessment but physio is limited.

Missing physiotherapist expertise.

C11: The treatment centre shall provide regular clinics for all PwBD, including women with bleeding disorders, to permit regular assessments on an appropriate schedule. (See Appendix 5, Recommended schedule for assessments.) Lack of medical resources to meet the usual deadlines.

22/26
85%

We have been falling behind on seeing patients, possibly due to COVID. We would need more "clinic time."

We have a weekly clinic - 3/4 weeks per month are general clinics while 1/month is for hemophilia & severe bleeding disorders. Physio generally comes to the hemophilia clinic only but is available as needed at other times based on her schedule. We do not have a clinic specifically for women with bleeding disorders; they are booked into the general or hemophilia clinic based on the bleeding disorder. We also do not have a dedicated transition clinic (C14), although there is continuity of care through nursing/PT/SW; it is only the physicians that differ between peds and adults.

We now have funding for 2 nurses in our clinic - an NP and an RN coordinator. We are hoping over the next couple years to develop their roles to offer specialty clinics (e.g. women with bleeding disorders), to develop new policies and guidelines, outreach, etc.

It would be nice to have more days available for patients so they have more choice.

Patients are not being seen annually as set out in the standards. Due to a lack of human resources, limited access to clinical space, and backlog due to COVID, patients with severe diseases are not being seen annually by any health care provider/team members.

We try but sometimes the wait list for follow up appointments is long and behind schedule. We so not see all mild patients on a regular basis as there are not enough resources to do so.

C12: The treatment centre shall collect detailed health outcomes over time. (See Appendix 4, Health outcomes to be measured.)

20/26
76%

ACTION - At next small group strategic meeting, discuss standard patient assessment points (e.g. bleed rate) at each visit and identify other outcomes (top 3?) to consider adding.

Hemophilia Joint Health Score (HJHS) not being completed at this time due to lack of a physiotherapist. Need creative strategies to permit safe and meaningful joint assessment. Continue to recruit for physiotherapist to complete HJHS.

MSK assessesment are only done on severe and moderate patients. Not all PwBD are assessed by PT. Mental health is not always discussed. I don't believe our HTC has training in basic mental health education and how to approch this topic or even what to ask or say. However, we have refered to psychology in the past for "obvious" reasons but surely some are falling through the cracks. Some basic socio-economic questions are asked, but I'm not sure our HTC follows through with what that means. SW does not come to Clinics. Very few patients have had PK testing. I'm not sure we keep track of the number of inpatient days due to bleeds (unless this data could be pulled from CBDR? because, when I am up to date with data entry, I do mark hospital admission). I don't believe time to Dx, first visit or initial treatment is data that we look at, but I could be wrong. Factor therapy half life or factor through levels are not done on most patients. Number of joints with imparments of structure or function is most likely documented on moderate and severe patients. Looking at Appendix 4, we are not able to do a full MSK assessement on all patients who would require it due to lack of physio time. We also don't collaborate with rheum/ortho/physiatry during our clinics like some other centres do. We do not have access to psychology services and have very little social work access.

Outcome measurement needs to continue to improve. Charting/documentation is a moving target with e-records coming online in province.

Not collected: QoL. Consider implementing tools for longitudinal monitoring of QoL. Remedial: Implement routine use of tools for longitudinal monitoring of QoL.

C13: The treatment centre shall maintain a record of patient/caregiver education.

22/26
85%

Education can be documented in the dictated patient letter, but there is no recertification of skills yearly, or after patients/parents have achieved initial compentency. Currently check in with patients during review visits, to determine their comfort level with skills, and address gaps in education.

Education is documented as part of patient chart but not in a separate record. Might be logged in ICHIP but unsure if we're consistent. No formal way of maintaining education record other than charting.

C14: The treatment centre shall coordinate care through transition (pediatric to adult, program to program, or province to province) to ensure continuity of care.

25.5/26
98%

ACTION send current transition checklist to pediatric/adult hematologists for review.

C15: The treatment centre shall respect all professional, institutional and provincial guidelines regarding patient privacy and confidentiality.

26/26
100%

No comments.

D: PATIENT/CAREGIVER EDUCATION AND SUPPORT

D1: The treatment centre shall provide information to PwBD and their families about clinical phenotype and therapeutic options relevant to their diagnosis.

26/26
100%

No comments.

D2: The treatment centre shall provide to PwBD/caregivers comprehensive information on treatment benefits and risks to make informed decisions.

26/26
100%

No comments.

D3: The treatment centre shall provide information about potential risks and benefits of physical activities and sports.

26/26
100%

Nursing felt although we provide info re risks & benefits of activity & sport, this is better addressed in the pediatric clinic as the PT is pediatric and has more time available for that population. Ideally we would like support for an adult physiotherapist with bleeding disorders as part of their job with more time to dedicate to our adult patients.

D4: The treatment centre shall provide access to genetic counselling delivered by an individual knowledgeable about inherited bleeding disorders.

24/26
92%

We have access to genetic testing but the counselling is not as readily available.

I have never had any "official" genetic education other than what I have read myself (in the very little spare time I have). I actually suggested genetics education as future CANHC topics as I realize this is very much lacking for me personally. However, I recently completed a Canadian Survey (one from out west) on genetics and it was VERY interesting (we should have them present for the HTCs.).

No specialized genetic counsellor in program and no formal education or learning sessions are set up separately from review visits.

Offered by HCPs in clinic, not by geneticist or genetic counsellor.

D5: The treatment centre shall provide, for PwBD/families on home-based care, comprehensive training about safe and responsible handling, storage, preparation and administration of treatment products, and safe disposal of used equipment and supplies.

25/26
96%

No comments.

D6: The treatment centre shall facilitate education and learning about current issues related to bleeding disorders to PwBD and their families.

26/26
100%

We have not provided webinars/education sessions recently, but would consider facilitating sessions in the upcoming year. Education is usually provided at patient visits.

Nursing felt we do provide this education although opportunities are limited - clinic & camp. Ideally we would like to offer other opportunities eg virtual evening talks, but we do not have support (financial, techinical, etc) for this. Overall we felt we are meeting these objectives but just so - there is one adult hematologist for the clinic who also works as a general hematologist (limited hours to dedicate to the clinic beyond patient care) and 2 nurses who split their time between the adult & peds populations. Within our time constraints we prioritize acute care of patients (bleeds, trauma, surgery, pregnancy), new referrals, plans of care (letters, FF cards), CBDR data entry. Although we can address education and support, we are limited in how much we can offer. <0.2 of the SW's position is for bleeding disorders - she is very helpful when we need her but are cognizant of not overburdening her. We do not have access to other counselling/psychologic support services unless the patient has private insurance. Given the lack of new funds in health care at the present time, we do not have ideas for remedial action to address this.

Physicians and nurse specialist provide patient education; however, we could improve with the expertise of social worker and physiotherapist.

D7: The treatment centre shall provide up-to-date documentation (e.g. *FactorFirst* wallet card) that identifies each person's bleeding disorder, recommended treatment plan and treatment centre contact information.

26/26
100%

No comments.

D8: The treatment centre shall inform PwBD and their caregivers whom to contact in the event of a bleeding episode.

26/26
100%

No comments.

D9: The treatment centre shall provide psychosocial support of the PwBD and family regarding schooling, employment and relationships, and the provision of social supports and counselling services.

13/26
50%

As nurses, we have strived to build good relationships with patients/families, and are able to provide support from a nursing standpoint. Unfortunately, while we do have SW FTE, they are unable to meet with the bleeding disorder patients/families, and they are only available on a referral basis currently (not always able to meet with families due to time conflicts).

We do not have a dedicated SW. We only provide some of this superficially and then refer to SW on an as needed basis.

Support lacking: employment counselling, social services.

Difficulty in accessing a psychologist at the hospital.

As nurses we provide basic psychosocial support but lack specialists: guidance counselor, social worker, psychologist.

Lack of social services.

Lacking: social work to help facilitate this.

We do not have access to phychosocial support staff. Very seldom social work referral for psychosocial support. Most referrals are for lack of financial support.

Limited dedicated SW for clinic.

Could use more SW time. Our patient population could benefit from community resources for social services (financial, equipment, emergency funding etc.).

Lacking: social worker.

Lacking: social worker.

Remedial: Increase funding for human resources.

We do not have a designated social worker. The physicians and nurses attempt to support the patients through discussions and providing available resources.

Offered by team members, not by social worker or psychologist.

D10: The treatment centre shall provide advice and support to ageing PwBD who require treatment for co-morbidities and to the health care providers who care for them.

24.5/26
94%

Not applicable as we are a paediatric centre.

Remedial action(s): check to see if the CHS already has documents related to ageing.

Lacking social worker/psychologist.

Population would benefit from a more formalised program for people ageing with hemophilia.

E: PRODUCT MONITORING

E1: The treatment centre shall maintain a list of all PwBD registered in the home therapy program.

26/26
100%

No comments.

E2: The treatment centre shall establish formal links to Canadian Blood Services or Héma-Québec for product ordering.

24/26
92%

No comments.

E3: The treatment centre shall be able to …

19.5/26
75%

a. **track home inventory in real time;**
b. **enter home inventory in electronic reporting systems;**
c. **account for and report the use of all factor concentrates and non-factor replacement therapies distributed to their registered patients;**
d. **monitor expiry dates of all factor concentrates and non-factor replacement therapies distributed to their registered patients;**
e. **be able to recall products within 24 hours.**

a, b. Yes (TML logs and sends daily reports) c. Yes (CBDR logs how/when used) d. Yes (in CBDR) e. Yes (TML staff responsible for recalls with assistance from bleeding disorder program if weekday).

The families are required to complete these records. We don't have the resources to enter the product for the families at the centre level. We have some families who do not use CBDR as they do not speak English. Remedial action: Advocate for data entry support.

Data manager and time needed to support patient updake with myCBDR then data management within the program. New secretary within the program just need to get them on board with training & support from management to do CBDR.

Partner with Hemophilia Ontario to communicate to the northern membership the importance of recording all bleeding episodes and treatment. Request chapter to attend during clinic to speak with patients and get them set up with myCBDR. Add myCBDR to annual assessment check list and speak to each patient about the importance of recording bleeds and treatments.

Patients enter their inventory themselves either by CBDR or paper.

Lacking: data manager; many of our patients are registered in our database, but we have not had the opportunity to use it to its full benefit as we have no resource to help with data entry.

It is very difficult to keep track of product usage unless they are doing accurately doing it themselves on MYCBDR. CBDR entry (by myself) has been increasingly time consuming since its start. I have

noticed, that as the only one who enters data, I am VERY behind. We NEED CBDR data entry person! We need to push for a full-time CBDR Data Entry or even increase our secretary to FT so she could help out with this. As much as we ask our PwBD to do this, they do not always comply. Often times, I e-mail them and ask them to do this but they do not. As much as I advocate for the importance of CBDR, only a small percentage keeps track. I can't withhold their factor, and so all I can do is keep asking them to do it. Very fustrating and time consuming.

We cannot track in real time. Products are still tracked in Meditech, so depend on patients returning cards. Accounting for use of all products is patient dependent as it relies on the patients completing and returning their cards.

The electronic system used by the health authority is problematic. A new system will be introduced in 2023, to be determined by the new HA. We are hopeful then to coordinate with X and possibly use CBDR/myCBDR so patients can more easily enter products used and allow for better/real time tracking.

Sometimes delays in entry of lot numbers dispensed by iCHIP support. Still rely on manual entry which is prone to transcription error. Not all factor is recorded; e.g. on-demand procedures. DDAVP not recorded. Not sure if we can track home inventory in real time and recall products within 24 hours?

E4: The treatment centre shall establish a mechanism whereby PwBD and their families record all bleeding episodes and treatments with clotting factor concentrates and non-factor replacement therapies so as to provide the treatment centre essential clinical data. As a condition of receiving home therapy, PwBD and their families shall be required to provide this information.

20.5/26
78%

Mechanisms exist (including nursing as the main data clerks), but reporting is not 100% universal (e.g. DDAVP for minor bleeds, delayed/lacking CBDR entries). It is a condition of home therapy, but missing information does not necessarily cancel access to home therapy.

Add myCBDR to annual assessment check list and speak to each patients about the importance of recording bleeds and treatments.

Partner with chapter to communicate to the northern membership the importance of recording all bleeding episodes and treatment. Request chapter to attend during clinic to speak with patients and get them setup with myCBDR.

With more nursing and data admin fundin,g this would allow closer follow-up and encouragement in patients' documenting treatments and bleeding events.

E5: The treatment centre shall report adverse events that occur in association with the administration of coagulation factor concentrates or non-factor replacement therapies, as mandated by the regulator, manufacturer or other appropriate body

26/26
100%

No comments.

F: HUMAN RESOURCES FOR INTEGRATED CARE

F1: The treatment centre shall maintain a complete complement of core team members which is adequate to meet these standards. (See Appendix 2, Team members and roles: Core and extended.)

10.5/26
40%

SW not always available due to time conflicts, continue to discuss patients with SW. NP can assist with some of the psychosocial issues medical management, basic physiotherapy tasks.

No SW; remedial action: advocate for SW.

Do not have the resources to double document between EPIC and CBDR. CBDR has data inputted but not all aspects of care, managed by CRA.

Have the skills for physio but unable to meet the guidelines due to inadequate staffing.

No physiotherapy.

No dedicated FTE for social worker or physio; available upon request.

No data manager.

Remedial: Present national standards to program director to illustrate without a data manager, the site is not able to meet the following standards: A2, C12, E3, E4 F2, H4.

We do not have a full complement of team members as we do not have a social worker, or nursing coverage when our full time nurse is away.

We lack social workers, psychologists.

Lacks a social worker, pain management expert, psychologist, psychiatrist, child specialist.

We have 1 FTE nurse, 2 hematologists (hemophilia clinic is staffed with 0.1 FTE hematologist, clinics are only 1/2 day per week and these clinics are attended by Dr. X 70% and Dr. Y 30%.) We also technically have a physiotherapist and a social worker assigned to us but they are very busy with other patients and not often available for our clinic.

Lacking: social work, Aadministrative assistance/data manager, coagulation lab staff is limited.

Have all core members but # of hours impacts adequacy. We have the complement however re PT & SW we feel the hours are inadequate.

Need more PT, SW, NP/RN and MD hours.

Zero social worker funding for the program. More time is required for nursing and physiotherapy.

Lacking: social worker, physiotherapist, increase nursing and data admin.

Missing: physio and social work.

Missing social worker, admin assistant, data manager, nursing only 3 days a week.

F2: The treatment centre shall be staffed with core team members who have the appropriate training and qualifications to provide care to the patient population. (See Appendix 7, Standards of care for core disciplines in bleeding disorder care.)

20.5/26
78%

No physiotherapy.

No data manager.

Again, missing social worker.

Only our nurse and physicians have specific training.

There is an onus on self-learning and learning in real time. There was limited overlap/orientation with prior nursing so insufficient time for transition of knowledge and skills specific to the care of patients with bleeding disorders. There is no formal education for nursing, most education comes from events offered by pharma, conferences, CANHC, CHS, etc.

Lacking: social worker, physiotherapist, increase nursing and data admin.

F3: The treatment centre shall have a process to monitor its ability to deliver care to the patient population and to request adjustments in human resources, when necessary.

14/26
54%

No official process to monitor care therefore, so no "physical proof" to increase staffing.

Yes, a process in in place but that doesn't equate to approval of adjustments in the current health care environment.

F4: The treatment centre shall provide a mechanism for team members to share knowledge with each other to promote best patient outcomes.

24.5/26
94%

Academic/Conference/TML/pharma updates that are dedicated to CME could be included/enhanced, and also include extended team members. ACTION: add to this week's staff meeting 5. A referral list exists but does not include the full complement of extended team members. ACTION: circulate current list and review at January staff meeting 8. There are no barriers for physicians, but membership in relevant organizations (ISTH? WFH?) could perhaps be expanded. For nursing, previous sources of funding will likely no longer be available. CANHC only gives membership to permanent nurses and will only fund 2 from each centre. ACTION: make list of "should join", "good to join, but not mandatory", "not necessary to join" organizations/conferences for each team member. ACTION: discuss nursing funding opportunities with SBDP manager.

F5: The treatment centre shall develop and maintain a referral list for extended team members and utilize their services as needed.

22/26
85%

Referrals are often sent to other specialists++. However, we do not have one particular contact/ physician for each specialty (extended team members) and no list is kept of who was consulted for whom.

Our program is constantly seeking community partners but some regions are less engaging.

F6: The treatment centre shall invite extended team members to team educational workshops and activities as appropriate.

20/26
77%

Improve linkages (formally) with regular specialty team members (ortho, GYN, Cardiac, GI) at our centre. We have some external practitioners we use but I wouldn't call them team members per say. Would be good to have a formal list with contact information to be consistent.

Remedial F: Reference material through hospital and CANHC, supported. Need more staff so team members can participate more in relevant organizations without putting a strain on the clinic for coverage, no formal referral list maintained.

F7: The treatment centre shall demonstrate collaboration among all team members

24/26
92%

No comments.

F8: The treatment centre shall facilitate core team members being members of relevant organizations and/or working groups within the bleeding disorder community and taking part in relevant education and training activities.

24.5/26
94%

No comments.

F9: The treatment centre shall facilitate access to reference materials for team members and students (e.g. AHCDC Clinical Practice Guidelines, journal articles and texts)

25.5/26
98%

Yes but limited by time constraints.

G: PHYSICAL RESOURCES

G1: The treatment centre shall have a clinical area sufficient for diagnosis and treatment that is age-appropriate, comfortable, quiet and adequately equipped, that respects privacy and confidentiality, and that is designed for people with disabilities or mobility aids.

18.5/26
71%

Missing clinic space, no stable space.

No space or stairs to safely perform HJHS in both the adult and pediatric clinics.

There is a terrible lack of rooms! No small, quiet space for teaching either new diagnosis or for teaching home treatment. Almost impossible to respect confidentiality. Corrective Action: Discuss with manager to find an isolated room for our teaching.

We do lack things for kids. Rooms are bare and kids are bored. Environment is not very child friendly. The beds used in clinic are not ideal for a physiotehrapy assessement. Plinths would be ideal vs stretchers. Beds are placed against the wall which makes assessment of bilateral limbs more difficult for patients as they have to change posititions which can be difficult for some. No way to assess stair climbing.

We use shared space in the hospital; no dedicated space for bleeding disorders. PT is in the pediatric hospital - some young adults refuse to see PT as a result.

Shared clinic space can limit multidisciplinary assessment and is not always ideal for people with disabilities. RAC space is quite small for people using gait or mobility aids. Also, our department is located up a long ramp which can be difficult for people with physical disabilities. We need dedicated space for clinicians to fully engage patients.

Conduct a needs assessment that will clarify the requirement for additional access to clinic space for ambulatory visits to minimize the burden on the Emergency Room that is excessively taxed during the pandemic. Present this data to the CLM to obtain access to ensure that emergent bleeding disorder care can be provided in the ambulatory setting.

Have to use space in the out-patient department, no dedicated space for hemophilia.

G2: The treatment centre shall be located in a facility that is linked with a day medicine department and an emergency department so that PwBD can obtain treatment.

26/26
100%

No comments.

H: INFORMATION SYSTEMS, HEALTH RECORDS, DATA COLLECTION

H1: The treatment centre shall follow provincial and institutional policies for maintaining records and assign a confidential identifier to each patient.

26/26
100%

No comments.

H2: The treatment centre shall document each patient's treatment plan, as appropriate, and review it annually.

23/26
88%

Not everyone treatment plan is reviewed annually. Data is entered only by nurse and sometimes very late being entered.

H3: The treatment centre shall be registered with a bleeding disorder registry database (e .g . CBDR, iCHIP) and ensure that all core team members have access to the information systems.

23/26
88%

Registration with database, Data current and routinely exported - Need access & education to other team members to CBDR.

Data current and routinely exported - Contact CBDR Program Manager to provide additional access & training on CBDR for new secretary.

My documentation is on the patient's hospital electronic record which all team members have access to. It is to hospital standards. I have access to CBDR but unfortunately rarely place data there. May not be the best use of time to chart patients data twice. As it stands, electronic charting is not very user friendly therefore notes are written and then later typed into computer.

H4: The treatment centre shall keep data current and routinely export data, as required, to the provincial and national databases.

21.5/26
83%

Data current and routinely exported - Unable to meet STANDARD H4 without meeting STANDARD F1.

Registration with database, Data current and routinely exported - Need access & education to other team members to CBDR.

Needs improvements to current data collection systems. SW documents in three systems at present; this is not ideal.

No data manager, suboptimal data updates to CBDR.

H5: The treatment centre shall collect detailed information concerning the outcomes of treatment. (See Appendix 4, Health outcomes to be measured.)

22/26
85%

Data is in paper charts with details (not all patient health outcomes in Appendix 4), but difficult to aggregate, especially at the clinic level. ACTION: await discussion with EMR team and strategy meeting series in early 2023.

Collecting treatment outcomes - As stated multiple times previously, no data manager therefore this is difficult to maintain and update regularly.

Not all patients are reviewed annually but the treatment plan is well documented. Documentation of outcomes is lacking due to lack of time.

Collecting outcome data but no formal reporting and how are we reporting it out. We should have an outcome dashboard on our website and outcome reporting should be Canada wide.

Severe and moderate patients are seen once every 1 to 2 years. Mild patients are seen PRN due to insufficient clinic space/time. We update CBDR, however, with extra admin staffing these records could be updated in more detail.

I: LINKAGES

I1: The treatment centre shall provide information on inherited bleeding disorders, contact information in case of emergency and treatment recommendations to emergency departments and primary care providers.

24/26
92%

Could update educational resources available on the hospital website.

We would be interested in learning from other centres on how we could improve on educating other health professionals and in particular ERs across our province.

I2: The treatment centre shall provide contact information and emergency treatment recommendations to the emergency department nearest to the PwBD's home.

22/26
85%

Some team membeers copy consult notes to patient's nearest hospital but not all and not always. Program provides information on demand during emergency situations. Need to provide more education to ERs, dentists and primary care>>more connection to provincial community.

We are working on a system to alert the ER departments of PwBD.

I3: The treatment centre shall provide education and treatment recommendations to other community professionals who provide services to PwBD (e.g. surgery, dentistry).

24.5/26
94%

Yes, but only as requested. We are limited by time and finances in terms of being able to offer educational opportunities.

I4: The treatment centre shall establish a process for referring PwBD to services not provided within the program.

24/26
92%

It may be recommended that patients seek further treatment at their local physiotherapy clinic/ hospital but there is no formal process. It is offered that clinicians call if they have any concerns.

I5: The treatment centre shall have a process in place to meet and discuss issues of mutual concern with the Canadian Hemophilia Society and its provincial chapters.

19/26
73%

Currently we don't have a process for meetings with the chapter. We used to have this but it was organized by the chapter but this has not happened in many years. We are available to talk to the chapter at any time.

We communicate with the CHS but do not have a process in place. If needed, we can arrange meetings and discussions.

Unfortunately, our provincial chapter is not currently active.

We are a small province so it is fairly easy for the chapter to contact us or to raise concerns during clinic visits.

No regular involvement with the BC Chapter.

I6: The treatment centre shall maintain current contact information for the treatment centre in listings with the Canadian Hemophilia Society, the World Federation of Hemophilia and parent hospital.

23.5/26
90%

Unsure. No request for updates from these organizations. ACTION: check current listings with the CHS, the WFH and ask about whose responsibility it is to reach out.

J: ACCREDITATION, AUDIT, QUALITY ASSURANCE, RESEARCH

J1: The treatment centre shall participate in hospital or peer evaluation and respond to critical appraisal.

24/26
92%

Not sure how to interpret the question. ACTION - ask the CHS to clarify/give examples of what this could look like.

I don't believe we have been "evaluated" since I have been in the role.

Not offered.

J2: The treatment centre shall participate in a formal accreditation and evaluation process, when established.

23/26
88%

I don't believe we have been "evaluated" since I have been in the role.

Not offered.

Hospital accrediation and college evaluation but no program evaluation.

J3: The treatment centre shall participate in research activities relevant to patients with bleeding disorders, where patient numbers and clinic resources permit such participation . Where this is not possible, treatment centres should endeavour to inform interested patients about opportunities to participate in research studies conducted in other treatment centres . (See Appendix 3, point 5.)

24/26
92%

Re opportunities at other centres, this is limited by patients' ability to pay. In general travel for clinical trials is not covered by insurance/provincial health care, so this would be limited to circumstances where the trial covers expenses for out-of-province patients and the centre is allowed to accept out-of-province participants.

J4: The treatment centre shall make known the institution's process to allow PwBD and families to communicate concerns, complaints and appreciation.

24/26
92%

Patient advocacy, safety line still available. Patient comment box no longer available during COVID. ACTION - nursing team will propose patient satisfaction survey in new year.

I don't know our institution's process, but I would direct patients to our nurse manager. That being said, I do not automatically make this known to PwBD and their families (only if one asks or complains).

The system to address complaints is not effective overall.

J5: The treatment centre shall have adequate physical and human resources to meet these standards

18/26
69%

Limited support has declined over the last several years, especially for study support.

No data manager. This document will be shared with senior management to illustrate the inability to meet the national standards for comprehensive care team.

It is not possible for the data manager to spend more time on CBDR. We stick to the basics. In order to provide more support to families and enter more data, we would need to train another person for CBDR. At this time, we do not have the budget to do so.

Remedial : Facilitate access to social workers and psychologists. Improve data entry into CBDR.

Adequate physical and human resources re quality assurance, research - Just barely adequate resources to meet standards for Inherited bleeding disorders. Not meeting acquired bleeding disorders standards. The Adult Program is always in a trail or catch up position when it comes to resources in relation to the standards outlined. We would need to increase staffing to meet high level standards and create more opportunities for patient centered workshops, etc.

Missing core team members (physiotherapy and social worker) and due to increase clinic numbers we can also benefit from increase nursing and admin support.

No social worker, nursing 3 days a week for 450-500 patients, no data manager, dedicated physiotherapist but very, very limited duties in hemophilia.

The main limiting factor is lack of adequate staffing. For documentation of teaching, this is something we could definitely improve on starting now. We could include a document in the paper chart to help keep track of what teaching was done and what documentation was given.

Look into educational options for our PT, SW and secretary. Inquire about the process of reviewing and updating policies and procedures and allocating time to this without falling behind on other things. As a group, meet and come up with better plan for bleeding patient follow-ups. Inquire with other HTCs to see how they follow up with patients who are not local. I have requested extra clinics on mutliple occasions but hematologists are overwhelmed with work demands already. As for detailed health outcomes, our HTC would need to become better at communicating as a team and have team meetings regarding our patients. Possibly get more team members involved (GYN, pediatrician, etc.).

More involvement, increased communication and collaboration needed between team members. Suggest regular meetings with other teams member to receive up to date information on treatments, education, specific patients and more. To attend clinics on a regular basis to ensure more visibility of service availability.

Social worker to attend clinic days to improve visibility of social work service.

No team meetings in place. Team members can discuss informally updates on patients simply because we sit in the same office but there is a sense of disconnect. There is no formal time set aside for a team meeting. To attend clinic meetings to receive information, education and increase collaboration. Education opportunities are not shared between team members and this would be very welcomed. Having regular team meetings. Consult outcomes should be shared with team members.

Improved access to pharmacy services to support PwH.

Increase access to clinic space for assessment of patients as needed.

Increase nursing and physiotherapy FTE.

Our team also covers the hemoglobinopathy population (an additional 254 patients) as part of our comprehensive care model. We do not have a data manager, but our unit clerk (1.0 FTE) does some data management.

FTEs: This is an approximatation of the numbers, not including my angioedema or Porphyria patients. The von Willebrand lists were deleted when our last nurse left, so they are slowly being rebuilt. The FTE's are also approximations, as our physio is a 0.5 shared with cystic fibrosis, and our social worker is 0.9, shared with hematology now, we no longer have data management, since CBDR replaced CHARMS, we have 1 full time product order clerk, who helps with CBDR and other admin work. There are also 2 other full time admin. clerks, but they all work together for all the portfolios: Bleeding, Hemophilia, Angioedema, Immunodeficiency, & Hemoglobinopathies. I am a 0.6 for the Bleeding, Hemophilia, Ehlors Danlos, Porphyria, and Angioedema portfolios. We have other nurses as well, 2 full time working with Immunodeficiency and 1 full time working with hemoglobinopathies. They cover the Hemophilia and Bleeding when I am not available.

Identify how social worker/psychosocial needs are being met through other team members, capture the impact on team members, work completed and what is lacking in care for the patient population. Clarify the RN/NP scope of practice and medical/legal implications for the individual and institution. Once the data indicates the RN/NP is acting outside of their scope of practice, highlight this to the institution. Illustrate how the program is not meeting the national standards of care, current staff are functioning out of scope, the safety risks for the patient population, and medical/legal risk for the staff and institution.

Draft a formal document to request a meeting with hospital leadership to lobby for additional programmatic funding.

Analyze the barriers leading to delays and insufficiencies in care. Identify facilitators that can be leveraged to enhance the likelihood of meeting the national standards.

OVERALL: ALL CENTRES REPORT CAPACITY TO RESPECT 88.8% OF STANDARDS.

REFERENCES

[1] Canadian Integrated and Comprehensive Care Standards for Inherited Bleeding Disorders. **bit.ly/StandardsOfCare2020**

[2] World Federation of Hemophilia, Guidelines for the Management of Hemophilia. **www1.wfh.org/publications/files/pdf-1863.pdf**

[3] Canadian Integrated and Comprehensive Care Standards for Inherited Bleeding Disorders, Self-assessment checklist **www.hemophilia.ca/integrated-and-comprehensive-care-standards**

[4] The Hemophilia Joint Health Score version 2.1 Validation in Adult Patients Study: A multicenter international study. St-Louis etal. **Res Pract Thromb Haemost.** 2022 Feb; 6(2): e12690.