



**CHS-MB Member Satisfaction Survey with the Manitoba Bleeding Disorders Program
(the Program)**

The Chapter is inviting you, as a client of the Manitoba Bleeding Disorders Program, to participate in a survey.

The Manitoba Bleeding Disorders Program was formally established as a provincial program in 2006 to provide quality comprehensive care to people diagnosed with congenital bleeding disorders. The Program consists of hematologists, nurses, physiotherapists and a social worker for both adults and children. The objective of this survey is to understand patients' experiences with the care and support they receive from the Program.

- Your participation is voluntary.
- You will not be asked to provide any personal information that could identify you or your family in any way.
- Your responses will be combined with the responses from other members; therefore, there is no way that your answers can be associated with you.
- The results of this survey will be presented by the Chapter to the Program so that we can continue to work together to ensure high quality care for our members.
- This survey will remain open until Friday, November 30th, 2018.
- We have included comments sections throughout the survey. We encourage you to share your experiences with us in an effort to gather meaningful data.
- If you cannot complete the entire survey by the deadline, please submit as much as you have completed. Any information we can gather will be useful.



Introduction

This survey was designed to gather information about your experiences with the Program.

It is divided into 5 Sections:

1. Basic information
2. Day to Day care and treatment
3. After-hours care and treatment
4. Patient/Family centered care
5. The Annual Assessment or “Clinic”

There are 49 questions in total, but not all questions will apply to all respondents.

It will take about 25 minutes to complete, but you can stop at any time and come back to it later.

If you are unable to complete the entire survey by the deadline, we would still like you to submit the responses you have been able to complete. Any information we receive will be helpful.

For the first time, we are inviting (female) **carriers** of bleeding disorders to participate. If you are both a carrier AND a parent of a minor child with a bleeding disorder, you can complete this survey TWICE- once as a parent and once as a carrier.

If you require a second copy of the survey, please email info@hemophiliamb.ca or call 204.775.8625 and we will gladly mail it to you!

Part 1.

First we want to ask you two questions about yourself. These are for classification purpose only. Your privacy will be protected and there will be no way to identify individuals in the final results of the survey.

1. **Are you:** (select only one)

- A person with a Bleeding disorder** including Von Willebrand Disease, rare Bleeding Disorders, Hemophilia A or B
- A parent** of a Child with a bleeding disorder including Von Willebrand Disease, rare Bleeding Disorders, Hemophilia A or B
- A carrier** (of Hemophilia A or B) symptomatic or non-symptomatic

2. **Do you live more than 100 km from Winnipeg?**

- Yes** **No**

Please continue to Part 2

Part 2: Questions about the Day-to Day Care:

These questions are about your experiences contacting the Program during “regular office hours”, that is, weekdays between 8:00 a.m. and 4:00 p.m. Regarding your experiences over the past year with the following program staff, how satisfied or dissatisfied are you that they respond in a timely manner when you page or call during regular office hours?

Please circle your answer:

3. Nurses about an issue with bleeding

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

4. Nurses about a non-bleeding issue

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

5. Physiotherapist

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

6. Social Worker

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

7. We welcome you to share your experiences with us:

8. How satisfied or dissatisfied are you that:

You can contact **any** program team member between your scheduled appointments?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

The program contacts you if they have a question about an entry that you made into “MyCBDR”?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

The Program gives you your test results in a timely manner?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

Part 2: Questions about the Day-to Day Care continued:

9. When you CALL the Program with a bleeding problem, how satisfied or dissatisfied are you with:

Please circle your answer:

The assessment that is done?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

The treatment plan you receive?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

10. When you COME IN with a bleeding problem, how satisfied or dissatisfied are you with:

The assessment that is done?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

The treatment plan you receive?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

11. We welcome you to share your experiences with us:

12. How satisfied or dissatisfied are you that:

All appropriate team members are notified and/or consulted when you have a bleed?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

The Program communicates with other professionals who are involved with your care (e.g., family physician, pain specialist, obstetrician, dentist)?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

The knowledge and training you received allows you to treat yourself/your child **at home**?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

Part 2, question 12 continued.... **How satisfied or dissatisfied are you that:**

You get the **supplies** you need for your treatments at home?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

The Program provides documentation and advice if you are travelling outside your usual health region (e.g., travel letter)?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

The Program notifies you if you have product that is about to expire?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

13. We welcome you to share your experiences with us:

Please continue to Part 3

Part 3: Questions about “After Hours” care:

These questions are about your experiences contacting the hematologist on call **OUTSIDE** of “regular office hours” that is **weekends, and evenings/overnight from 4 pm to 8 am** weekdays.

Please circle your answer:

14. How satisfied or dissatisfied are you that you cannot page the Program Nurses outside of regular office hours?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

15. Have you ever paged the Hematologist-on-call after hours?

Yes No

If “No”, skip to Part 4.

16. If yes: How satisfied or dissatisfied were you that:

He/she responded in a timely manner?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

He/she had access to your personal history and treatment plan?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

He/she provided appropriate advice?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

If a visit to the ER was deemed necessary, he/she gave enough information to the ER to coordinate your care?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

He/she notified the Program nurses about your call and the treatment recommendations that were given?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

The Program nurses contacted you to follow-up regarding your after-hours call?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

Either the hematologist-on-call OR the Program Nurses made sure that other team members were notified of your condition as necessary (e.g. physiotherapy, referral to other specialist)?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

17. Comments about after-hours care:

Please continue to Part 4

Part 4: Your partnership with the Program

CHS-MC promotes an **active partnership** between the persons living with bleeding disorders and the comprehensive care team. These next questions will ask about **your partnership** with the Manitoba Bleeding Disorders Program.

Please circle your answer:

18. How satisfied or dissatisfied are you that the Program:

Refers you to sources of credible educational resources that can help you be a good partner in the management of your bleeding disorder (e.g. Canadian Hemophilia Society website, blogs, apps)?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

Develops a treatment plan that respects your family's values and preferences?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

Welcomes family members or other support people to attend appointments with you?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

Acknowledges changes associated with different life stages especially adolescence and aging) by modifying the treatment plan accordingly?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

Identifies potential carriers and initiates testing counselling and treatment as appropriate?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

Helps you to access health services or see specialists **outside the bleeding disorders team** (e.g., ER, surgeons, in-patient wards)?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

Acknowledges the challenges financial burden of living with an inherited bleeding disorder by connecting you with appropriate social services?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

Helps you communicate with your school or workplace if you need to make special arrangements because of your/your child's bleeding disorder?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

Provides ways for you to express your concerns or compliments?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

Part 4: Your partnership with the Program continued:

19. We welcome you to share your experiences with us:

Please continue to Part 5

Part 5: Questions about the Annual Assessment (“Clinic”):

National and international guidelines recommend that all **people with bleeding disorders should be seen at least once a year by all Core team members** (Physician, nurse-coordinator, physiotherapist and social worker) for evaluation.

The purpose of this assessment is:

- To monitor health status
- To identify new or potential problems so treatment can be modified
- To provide a COMPLETE evaluation of blood work, joint and muscle status, and overall well-being
- to develop/audit/refine each individual’s management plan
- to refer to other specialists if necessary

These next questions ask about your experience with your visits to “Clinic”.

20. How often are you/your child seen by the whole team for a complete check-up?

- Twice a year
- Once a year
- Every 18 months to 2 years
- I have never had a full checkup by all team members
- Other _____

Part 5: Questions about the Annual Assessment (“Clinic”) continued:

Please circle your answer:

21. At clinic, how satisfied or dissatisfied are you that you have the opportunity to discuss:

Your/your child’s bleeding patterns and review your bleeding diary?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

Any challenges or difficulties you are having with your HOME treatments?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

Your bleed prevention and control plan?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

Whether you have chronic and ongoing pain and if so, how you manage it?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

Your/your child’s physical activity level and overall health?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

The challenges you and your family face while living with a bleeding disorder (such as issues at school or work, ability to participate in social or leisure activities)?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

22. We welcome you to share your experiences with us:

Part 5: Questions about the Annual Assessment (“Clinic”) continued:

Please circle your answer:

23. At clinic, how satisfied or dissatisfied are you that you have the opportunity to:

Have your joints and muscles assessed?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

Update your Factor First Card if there are changes to your status or treatments?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

Discuss other treatment options that may be available?

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied Not applicable to me

24. Any last things you would like to share with us?

End of Survey.

Thank you for taking the time to give us your feedback!

A summary of the findings will be published on the Chapter website.