PROBE

Patient Reported Outcomes Burdens and Experiences Study

The Canadian Hemophilia Society and the Patient Reported Outcomes Burdens and Experiences (PROBE) study group invite you to participate in a multinational, patient-focused research study to investigate and directly probe patient perspectives on outcomes that affect your own life and care.

The research will support advocacy to improve care for you and others within the hemophilia community. We appreciate your willingness to participate in this survey. The survey will take approximately 15 minutes to complete. You will be asked personal questions about your hemophilia's severity, your age, your treatment history and the impact of hemophilia on your daily living.

The PROBE study group would like to assure you that your responses to survey questions will not be connected to you individually. All responses will have identifying information removed and be combined with those from other respondents. A summary report will be provided to the Canadian Hemophilia Society.

The PROBE study group is a global team of investigators with administrative support from the U.S. National Hemophilia Foundation. Should you have any questions about the survey, you may contact the study team at PROBE@hemophilia.org or your local patient organization (David Page, dpage@hemophilia.ca, 1-514-848-0503 Ext. 224).

PERSONAL

1. Country: _____

2. What type of bleeding disorder do you have?
   - ☐ Hemophilia A (FVIII). **Please proceed.**
   - ☐ Hemophilia B (FIX). **Please proceed.**
   - ☐ I have a bleeding disorder other than hemophilia. **Please stop**. Thank you for your interest. However, you do not qualify to participate in this survey. Future research will address other bleeding disorders.
   - ☐ I do not personally have hemophilia or any other bleeding disorder. **Please proceed.** The responses of individuals without a bleeding disorder are very important to our research analysis. Please answer the questions for yourself if you are a parent or caregiver of a child with a bleeding disorder. Do not answer for your child.

3. Year of Birth: _____

4. Gender:
   - ☐ Female
   - ☐ Male

5. Weight in kilograms (kg): _____ or weight in pounds (lbs.): _____

6. How old were you when you first started school? Please fill in the blank: _____

   How many years of school/education have you completed (include years studying for a vocational, professional or advanced degree)? Please fill in the blank: _____

SURVEY CONTINUES ON NEXT PAGE. PLEASE CONTINUE.

7. Are you married or in a long-term relationship?
   - ☐ Yes
   - ☐ No

   Do you have children?
   - ☐ Yes
   - ☐ No

PROBLEMS

8. In the past 12 months, have you experienced any problems related to your health?
   - ☐ Yes
   - ☐ No

   If yes, please list your top 3 problems in order of seriousness:

   1. _____
   2. _____
   3. _____

9. In the past 12 months, did you use a mobility aid or assistive device?
   - ☐ Yes
   - ☐ No

   If yes, please indicate the frequency with which you used each mobility aid or assistive device.

	Never (0% of the time)	Rarely (1–5% of the time)	Occasionally (6–25% of the time)	Sometimes (26–50% of the time)	Frequently (51–75% of the time)	Very frequently (76–99% of the time)	Always (100% of the time)
Compression bandage/wrap	☐	☐	☐	☐	☐	☐	☐
Orthopaedic brace	☐	☐	☐	☐	☐	☐	☐
Sling	☐	☐	☐	☐	☐	☐	☐
Cane	☐	☐	☐	☐	☐	☐	☐
Crutches	☐	☐	☐	☐	☐	☐	☐
Walker	☐	☐	☐	☐	☐	☐	☐
Manual wheelchair	☐	☐	☐	☐	☐	☐	☐
Motorized wheelchair	☐	☐	☐	☐	☐	☐	☐
Electric scooter	☐	☐	☐	☐	☐	☐	☐
Other (Describe): _____	☐	☐	☐	☐	☐	☐	☐

SURVEY CONTINUES ON NEXT PAGE. PLEASE CONTINUE.

10. Do you currently have any of the following? (Please check all that apply.)
- ☐ Hepatitis B
- ☐ Hepatitis C
- ☐ HIV

11. During the past 12 months did you use any medication for pain?
- ☐ Yes
- ☐ No

If yes, please estimate the percent of the time you used pain medication.
- ❑ Never (0% of the time)
- ❑ Rarely (1–5% of the time)
- ❑ Occasionally (6–25% of the time)
- ❑ Sometimes (26%–50% of the time)
- ❑ Frequently (51%–75% of the time)
- ❑ Very frequently (76%–99% of the time)
- ❑ All of the time (100% of the time)

12. "Acute pain" is defined as pain that arises in response to an event (like an injury or bleeding episode). "Acute pain" does not include "chronic pain." "Chronic pain" is defined as pain from a persistent cause; it can vary in frequency and intensity (like back pain, pain from sore joints, or arthropathy). During the past 12 months, have you experienced acute pain?
- ☐ Yes
- ☐ No

If yes, when did your acute pain occur? (Please check all that apply.)
- ☐ Walking
- ☐ Stair climbing
- ☐ Nighttime (such as waking you up/keeping you awake)
- ☐ Resting
- ☐ Weight bearing
- ☐ Other (Describe): _____

If yes, did your acute pain interfere with any of the following? (Please check all that apply.)
- ☐ General activity
- ☐ Mood
- ☐ Walking ability
- ☐ Normal work (including both work outside the home and housework)
- ☐ Attending school
- ☐ Relations with others
- ☐ Sleep
- ☐ Enjoyment of life
- ☐ Other (Describe): _____

SURVEY CONTINUES ON NEXT PAGE. PLEASE CONTINUE.

13. "Chronic pain" is defined as pain from a persistent cause; it can vary in frequency and intensity (like back pain, pain from sore joints, or arthropathy). "Chronic pain" does not include "acute pain." "Acute pain" is defined as pain that arises in response to an event (like an injury or bleeding episode). During the past 12 months, have you experienced chronic pain?

- ☐ Yes
- ☐ No

If yes, when does your chronic pain occur? (Please check all that apply.)

- ☐ Walking
- ☐ Stair climbing
- ☐ Nighttime (such as waking you up/keeping you awake)
- ☐ Resting
- ☐ Weight bearing
- ☐ Other (Describe): _____

If yes, does your chronic pain interfere with any of the following? (Please check all that apply.)

- ☐ General activity
- ☐ Mood
- ☐ Walking ability
- ☐ Normal work (including both work outside the home and housework)
- ☐ Attending school
- ☐ Relations with others
- ☐ Sleep
- ☐ Enjoyment of life
- ☐ Other (Describe): _____

14. Do you currently have difficulty with any activities of daily living?

- ☐ Yes
- ☐ No

If yes, please check all that apply:

- ☐ Going down stairs
- ☐ Going up stairs
- ☐ Rising from sitting
- ☐ Standing
- ☐ Bending to floor
- ☐ Walking on flat surfaces
- ☐ Getting in/out of car
- ☐ Going shopping
- ☐ Putting on socks
- ☐ Lying in bed
- ☐ Taking off socks
- ☐ Rising from bed
- ☐ Getting in/out of bath
- ☐ Sitting
- ☐ Getting on/off toilet
- ☐ Heavy domestic duties
- ☐ Light domestic duties
- ☐ Lifting
- ☐ Writing or typing
- ☐ Grooming
- ☐ Sexual intimacy
- ☐ Other (Describe): _____

SURVEY CONTINUES ON NEXT PAGE. PLEASE CONTINUE.

15. Please select the best answer to describe your current work and/or school life.

- ☐ Working full-time
- ☐ Working part-time (Estimate percentage of full-time hours: _____ %)
  If you are working part-time, is this by your personal choice?
  - ☐ Yes
  - ☐ No
- ☐ Student full-time
- ☐ Student part-time
- ☐ On long-term sick or disability leave (more than 6 months)
- ☐ Early retirement (prior to normal retirement age)
  If you retired early, was this by your personal choice?
  - ☐ Yes
  - ☐ No
- ☐ Other (such as unemployed, on parental leave, retired). Please describe: _____

How many days during the past 12 months were you not able to leave your home to go to work, attend school or participate in your normal daily activities due to health related reasons? _____

16. Have you ever gone through joint surgery or another invasive procedure (operation)?

- ☐ Yes
- ☐ No

If yes, please check all that apply:

- ☐ Aspiration (removal of fluid, gas or biopsy specimen by suction)
- ☐ Amputation (surgical removal of limb or body part)
- ☐ Joint replacement (arthroplasty)
- ☐ Joint fusion (arthrodesis)
- ☐ Radio or chemical synovectomy (removal of joint lining)
- ☐ Surgical synovectomy (removal of joint lining)
- ☐ Surgery for removal of a pseudotumor
- ☐ Other (Please describe): _____

If yes, how many joint surgeries or other invasive procedures (operations) have you ever gone through?

- ☐ 0
- ☐ 1
- ☐ 2-3
- ☐ 4-7
- ☐ 8-10
- ☐ More than 10

SURVEY CONTINUES ON NEXT PAGE. PLEASE CONTINUE.

HEMOPHILIA-RELATED QUESTIONS

IF YOU DO NOT PERSONALLY HAVE HEMOPHILIA, PLEASE SKIP TO QUESTION 28. THE FOLLOWING SECTION IS ONLY TO BE COMPLETED DIRECTLY BY PATIENTS THEMSELVES. PARENTS AND CAREGIVERS SHOULD NOT COMPLETE THIS SECTION FOR THEIR CHILDREN.

17. How severe is your hemophilia?
- ☐ Severe (Factor level below 1%)
- ☐ Moderate (Factor level 1-5%)
- ☐ Mild (Factor level above 5%)
- ☐ I do not know

18. A "clinically significant" inhibitor is defined as not responding to normal treatment. Have you ever been diagnosed with a clinically significant inhibitor?
- ☐ Yes
- ☐ No
- ☐ I do not know

If yes, do you currently have a clinically significant inhibitor?
- ☐ Yes
- ☐ No

19. How many bleeds did you have in the past 12 months?
- ☐ 0 bleeds
- ☐ 1 bleed
- ☐ 2-3 bleeds
- ☐ 4-7 bleeds
- ☐ 8-10 bleeds
- ☐ 11-15 bleeds
- ☐ 16-30 bleeds
- ☐ More than 30 bleeds

20. Within the past two weeks, have you had a bleed?
- ☐ Yes
- ☐ No

If yes, please describe: _____

21. Where do you receive your regular treatment?
- ☐ Home
- ☐ Hemophilia treatment centre (HTC)
- ☐ Emergency room
- ☐ Other (Please specify): _____
- ☐ No treatment available

22. What is your current treatment regimen?
- ☐ Regular prophylaxis (Regular, continuous treatment to prevent bleeds with an intent to treat for 52 weeks of the year)
- ☐ Intermittent, "periodic" prophylaxis (Treatment given to prevent bleeding before a specific activity or for short periods of time, not more than 45 weeks in a year)
- ☐ Episodic ("on-demand") (Treatment given at the time of clinically evident bleeding)
- ☐ Immune tolerance induction (ITI) (Treatment to overcome an inhibitor)
- ☐ No treatment available

SURVEY CONTINUES ON NEXT PAGE. PLEASE CONTINUE.

23. How do you currently treat? If you treat with a combination of regimens, please indicate all that apply.

Prophylaxis (Regular or Intermittent) with Factor Concentrate	Episodic ("On-Demand") with Factor Concentrate	Other Treatment
Typical dose of Factor VIII/IX concentrate used. Please indicate IUs per infusion: _____	Typical dose of Factor VIII/IX concentrate used per infusion. Please indicate IUs per infusion: _____	You use products other than Factor VIII/IX concentrates: ☐ Whole blood transfusions ☐ Fresh-frozen plasma ☐ Cryoprecipitate ☐ Antifibrinolytics (e.g., tranexamic acid or aminocaproic acid) ☐ Desmopressin (DDAVP) ☐ Bypassing agents ☐ Other therapies (Please describe): _____
Typical prophylaxis frequency: ☐ Daily ☐ Every other day ☐ 3 times per week ☐ 2 times per week ☐ Once per week ☐ Other (Please describe): _____	Number of infusions typically required to treat a bleeding episode: ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ More than 5	
Do you currently use an extended (prolonged) half-life treatment product? ☐ Yes ☐ No	Do you currently use an extended (prolonged) half-life treatment product? ☐ Yes ☐ No	

24. Please give a brief history of your treatment regimens during your lifetime. (Provide your best estimate or approximate age.)

	From Age	To Age	Treatment regimen
Example	0	2	No treatment
Example	2	3	On demand with cryo
Example	4	5	Immune tolerance
Example	6	21	Regular prophylaxis with factor
Example	22	Present	On demand with factor
1			
2			
3			
4			
5			
6			
7			

SURVEY CONTINUES ON NEXT PAGE. PLEASE CONTINUE.

25. Do you currently have any "target joints"?

- ☐ Yes
- ☐ No
- ☐ I do not know

If yes, which joint(s)? (Please check all that apply.)

- ☐ Left ankle
- ☐ Right ankle
- ☐ Left elbow
- ☐ Right elbow
- ☐ Left knee
- ☐ Right knee
- ☐ Other (Describe): _____

If yes, have you had more than 2 spontaneous bleeds (including those resulting from normal daily activity) into any of these joints in the past 12 months?

- ☐ Yes
- ☐ No
- ☐ I do not know

26. Is the range of motion of any joint currently reduced because of your having hemophilia?

- ☐ Yes
- ☐ No

If yes, which joint(s)? (Please check all that apply.)

- ☐ Left ankle
- ☐ Right ankle
- ☐ Left elbow
- ☐ Right elbow
- ☐ Left knee
- ☐ Right knee
- ☐ Other (Describe): _____

27. Other than joint bleeds, have you had any life- or limb-threatening bleeds in the past 12 months?

- ☐ Yes
- ☐ No

If yes, please check all that apply:

- ☐ Calf
- ☐ Dental
- ☐ Forearm
- ☐ Gastrointestinal
- ☐ Head/intracranial hemorrhage (ICH)
- ☐ Iliopsoas
- ☐ Internal organ (e.g., kidney, liver)
- ☐ Bleeding related to childbirth
- ☐ Bleeding related to menstruation
- ☐ Bleeding related to surgery
- ☐ Other (Please describe): _____

SURVEY CONTINUES ON NEXT PAGE. PLEASE CONTINUE.

28. Under each heading, please check ONE box that best describes your health TODAY.

MOBILITY

I have no problems walking	❑
I have slight problems walking	❑
I have moderate problems walking	❑
I have severe problems walking	❑
I am unable to walk	❑

SELF-CARE

I have no problems washing or dressing myself	❑
I have slight problems washing or dressing myself	❑
I have moderate problems washing or dressing myself	❑
I have severe problems washing or dressing myself	❑
I am unable to wash or dress myself	❑

USUAL ACTIVITIES *(e.g. work, study, housework, family or leisure activities)*

I have no problems doing my usual activities	❑
I have slight problems doing my usual activities	❑
I have moderate problems doing my usual activities	❑
I have severe problems doing my usual activities	❑
I am unable to do my usual activities	❑

PAIN/DISCOMFORT

I have no pain or discomfort	❑
I have slight pain or discomfort	❑
I have moderate pain or discomfort	❑
I have severe pain or discomfort	❑
I have extreme pain or discomfort	❑

ANXIETY/DEPRESSION

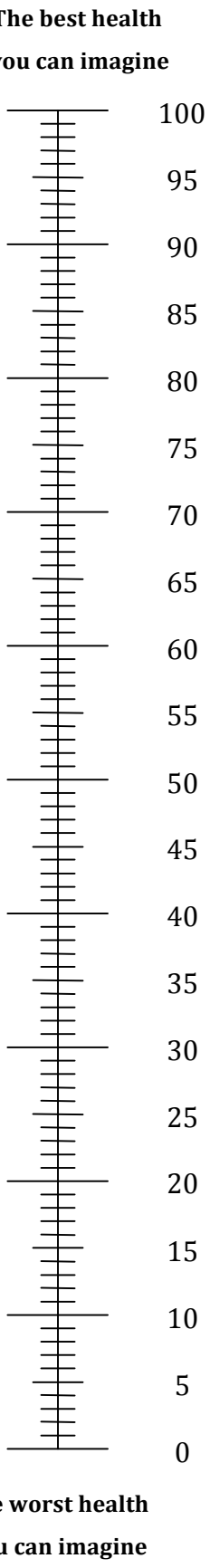
I am not anxious or depressed	❑
I am slightly anxious or depressed	❑
I am moderately anxious or depressed	❑
I am severely anxious or depressed	❑
I am extremely anxious or depressed	❑

SURVEY CONTINUES ON NEXT PAGE. PLEASE CONTINUE.

We would like to know how good or bad your health is TODAY.

- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.
  0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY = ☐



SURVEY CONTINUES ON NEXT PAGE. PLEASE CONTINUE.

29. What is your primary language? (Please fill in the blank.) _____

30. How long did this questionnaire take you to complete?
- ☐ 0-15 minutes
- ☐ 16-20 minutes
- ☐ 21-25 minutes
- ☐ 26-30 minutes
- ☐ More than 30 minutes

END OF SURVEY

Thank you for your participation! You may tear off the last page of this survey, date it and keep it as proof of your participation in the PROBE study.

Date: _____

PLEASE RETAIN THIS PAGE FOR YOUR PERSONAL RECORDS.
IT WILL SERVE AS A RECEIPT OF YOUR PARTICIPATION IN THE PROBE STUDY.

The Canadian Hemophilia Society and the Patient Reported Outcomes Burdens and Experiences (PROBE) study group thank you for your participation in this study. PROBE is a multinational, patient-focused research study to investigate and directly probe patient perspectives on outcomes relevant to your own life and care.

The research will support advocacy to improve care for you and others within the hemophilia community. We appreciate your willingness to participate in this survey.

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Thank you for your participation!