

Patient Experience of Care Survey

Thank you for completing this form. Your answers will help us improve care to our patients. Please complete this for only one person. For multiple siblings seen at one clinic, please complete one survey per patient. If you are 18-22 years old, please complete this survey yourself. If you are 12-17 years old, please complete with the supervision of a parent or guardian. For this survey, patient refers to anyone with a bleeding disorder who is 12-22 years old.

Please complete question below:

1. **Date:** _____
2. **How old are you?**
_____ years

Please circle your answers below:

3. **What is your gender?**

Male Female

4. **What is your diagnosis?**

Hemophilia A or B (Factor 8 or 9 deficiency)

Von Willebrand Disease

Platelet disorder

Other bleeding disorder

I do not know my/my child's disorder

5. **What is your ethnicity?**

Hispanic or Latino

Not Hispanic or Latino

6. **What is your race? (please circle all that apply)**

American Indian or Alaska Native Asian

Black or African American

Native Hawaiian or other Pacific Islander

Asian or Asian American

White or Caucasian

Other

Please Turn Over to Complete Questionnaire



The following questions are about the patient’s experience in this bleeding disorders clinic. Your responses will be grouped with others so we may learn how to provide better care. You will not be contacted after completing the survey.

7. During the past 12 months, how many times were you seen by your HTC?

1 time 2 times 3-6 times 6 or more times

8. Have the healthcare providers at this clinic talked to you about your bleeding disorder health care needs as you become an adult?

Yes No I am not sure

If no: Would a discussion about your health care needs as they relate to your bleeding disorder have been helpful?

Yes No I am not sure

9. Have the healthcare providers at this clinic encouraged you to take responsibility for managing the bleeding disorder (such as using medication, understanding your diagnosis, recognizing bleeds, following medical advice, making healthy lifestyle choices)?

Yes No I am not sure

If yes: How often do the healthcare providers at this clinic encourage you to take responsibility for managing your bleeding disorder?

Always (every visit) Usually (most visits) Sometimes (some visits) Never (no visits)

10. Have the healthcare providers at this clinic talked to you about how you can obtain or keep health insurance coverage as you become an adult?

Yes No I am not sure

If no: Would a discussion about health insurance have been helpful to you?

Yes No I am not sure

11. During the past 12 months did the clinic staff talk with you about eventually seeing doctors who treat adults with bleeding disorders?

Yes No I am not sure

If no: Would you like to talk to the clinic staff about doctors that treat adults with bleeding disorders?

Yes No I am not sure

Thank you for taking the time to provide information about your care. If you have any questions about this survey, or about your care, please contact your HTC nurse coordinator.