

**HANDI Focus Group Study
Young Adults Aged 16–17 Living With Hemophilia
Respondent Screener**

General Recruiting Criteria:

- Recruit young adult males and females aged 16–17 years living with hemophilia.
- Recruit young adult participants with different levels of severity.
- Must not have participated in a focus group within the last 6 months.

General Notes

- Please recruit 10 to ensure that 6 to 8 participants are in each group.
- Young adult participants will receive a \$50 cash incentive and, if one of the first 10 participants to qualify, an iTunes gift card valued at \$15.
- Consent of the youth and the parent must be obtained.
- Recruiter will call parent/guardian to verify their signature granting parental consent for their child to participate in the focus group.
- Each focus group will last approximately 90 minutes.
- All focus groups will be audio taped; The audio tape will be made available to the moderator immediately after the focus group.
- The identity of the focus group participants must remain private.
- All participants will be asked to use their first name only in the focus group.
- All participants must be fluent in English (determined by phone conversation with the recruiter).
- Groups will be observed by staff from the Centers for Disease Control and Prevention (CDC), the National Hemophilia Foundation (NHF), and ICF Macro.
- Participants do not have to answer any questions that they do not want to, but they are encouraged to participate.
- No more than one youth may be recruited from the same household.

Focus Group Schedule:

Date	Time	Participants
TBD	TBD	Young adults aged 16–17 years living with hemophilia

Interviewer/Recruiter’s Text:

Once a participant calls to inquire about this study, ask to speak to a parent/guardian first. If a parent/guardian is not able to provide consent, please ask participant to call back when a parent/guardian is available to give the recruiter permission to screen the child.

Read the following statement to the parent/guardian:

- Hello, my name is _____. I am from [insert name of facility]. We are recruiting young adults aged 16–17 years living with hemophilia to participate in a research project on behalf of the Centers for Disease Control and Prevention (CDC) and the National Hemophilia Foundation (NHF). Your child’s participation will help the CDC and NHF to gain a better understanding of what messages or information is important to communicate to persons your age living with hemophilia. If selected, your child will receive an incentive of \$50, and if one of the first 10 participants to qualify, an iTunes gift card valued at \$15.

Do I have your permission to screen your child to see if he/she is eligible to participate?

_____ Yes [Continue with the questions below.]

_____ No [Thank you; end call]

Please document name of parent/guardian: _____

Note to screener: If the person is not familiar with a telephone focus group, please read the following definition:

A telephone focus group is when you gather on toll-free telephone line a group of six to eight people, who have been selected because they have something in common, to get their thoughts and opinions about a particular issue, product, service, or idea. The telephone focus group is led by a person who is experienced and trained in leading a discussion with the group participants.

1. May I ask you a few questions to see if you are eligible to participate in this study?

_____ Yes [Continue]

_____ No [Thank you; end call]

2. Have you participated in a focus group within the last 6 months?

_____ Yes [Thank you; end call]

_____ No [Continue]

3. What is your age?

_____ 16–17 [Continue]

_____ Less than age 16 [Thank you; end call]

_____ 18–19
[if eligible, recruit and screen for group with young adults 18–19]

_____ 20 and over [Thank you; end call]

4. Have you or any member of your immediate family ever worked for the following organizations:

_____ CDC [If yes, thank you; end call]

_____ NHF [If yes, thank you; end call]

_____ Hemophilia research or treatment center [If yes, thank you; end call]

_____ Marketing research firm [If yes, thank you; end call]

_____ None of the above [Continue]

5. Have you been diagnosed with hemophilia?

_____ Yes [Continue]

_____ No [Thank you; end call]

6. What type of hemophilia do you have?

_____ Hemophilia A/Factor VIII deficiency [Continue]

_____ Hemophilia B/Factor IX deficiency [Continue]

_____ Von Willebrand disease or other clotting disorder [Thank you; end call]

7. What is the severity of hemophilia that you have? [Gather the information; not an exclusive or inclusive criterion]

_____ Mild [Continue]

_____ Moderate [Continue]

_____ Severe [Continue]

_____ Don't know [Continue]

[Note to recruiter: if respondent is not familiar with the terms mild, moderate or severe hemophilia provide the respondent with the following definition.]

Hemophilia is classified as mild, moderate, or severe, based on the amount of the clotting factor in the person's blood. If someone produces only 1% or less of the affected factor, the case is called severe. Someone that produces 2% to 5% has a moderate case, and someone that produces 6% to 50% of the affected factor level is considered to have a mild case of hemophilia. In general, a person with milder hemophilia may only bleed excessively once in a while, whereas severe hemophilia puts someone at risk for having bleeding problems much more often.

8. What is your gender/sex? [Gather the information; not an inclusive/exclusive question]

_____ Male [Continue]

_____ Female [Continue]

9. What is your race/ethnicity? [Gather the information; not an inclusive/exclusive question]

Ethnicity:

€ Hispanic Origin [Continue]

€ Not of Hispanic Origin [Continue]

€ Refused to answer [Continue]

Race:

€ American Indian or Alaskan Native [Continue]

€ Asian [Continue]

€ Hawaiian or other Pacific Islander [Continue]

€ Black or African American [Continue]

€ White or Caucasian [Continue]

€ Refused [Continue]

10. What is the highest level of education that you have completed? [Gather the information; not an inclusive/exclusive question]

- € Less than high school [Continue]
- € High school graduate or GED [Continue]
- € Technical/vocational school [Continue]
- € College [Continue]

We would like to invite you to participate in a telephone focus group with six to eight other young adults in your age group. This telephone focus group will gather your opinions about delivering messages and information to young adults living with hemophilia. The focus group will last approximately 90 minutes and will be audio taped; however, your participation in the focus group will remain private.

The telephone focus group will take place on _____ at _____ p.m. You will be sent a toll-free number and instructions for dialing into the call prior to the group.

Termination Script: I'm sorry, but we are currently looking for people who fit a different profile. Thank you for your time and interest in this research.

Will you be available to participate at this time?

_____ Yes [Continue]

_____ No [Thank you; end call]

I am pleased that you will be able to join us. I would like to send you and your parent/guardian a confirmation letter. In order to participate in the focus group, you and your parent/guardian will need to sign the consent form. All parent/guardian signatures will be verified. Please share with me your contact information, which will be private and not shared with anyone.

Youth Name _____

Address _____

City _____ State _____ Zip _____

Day Phone _____ Evening Phone _____

Cell Phone _____ FAX _____

E-mail _____

Parent/Guardian Name _____

Address _____

City _____ State _____ Zip _____

Day Phone _____ Evening Phone _____

Cell Phone _____ FAX _____

E-mail _____

Confirm:

Date of Telephone Focus Group _____ Time _____

Thank you very much. I appreciate your taking time to respond to my questions and look forward to your participation in this telephone focus group.