

**HANDI Focus Group Study
Parents of Children Aged 5–12 Years or Parents of Teenagers/Young Adults Living
With Hemophilia
Respondent Screener**

General Recruiting Criteria:

- Recruit a mix of adult parents of children aged 5–12 years or parents of teenagers/young adults aged 16–19 years living with hemophilia.
- Recruit a mix of males and females.
- 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.
- Participants will receive a \$50 cash incentive.
- 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 must be fluent in English (determined by phone conversation with 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 parent/guardian may be recruited from the same household.

Focus Group Schedule:

| Date | Time | Participants |
|------|------|--|
| TBD | TBD | Parents of children aged 5–12 years or parents of teenagers/young adults aged 16–19 years living with hemophilia |

Public reporting burden of this collection of information is estimated to average 12 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to CDC/ATSDR Information Clearance Officer, 1600 Clifton Road N.E., MS D-74, Atlanta, Georgia 30333, ATTN: PRA (0920-0858).

Interviewer/Recruiter's Text:

Hello, my name is _____. I am calling from [insert name of facility]. We are recruiting parents of children aged 5–12 years or parents of teenagers/young adults 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 participation would help us to gain a better understanding of what messages or information is important to communicate to young adults living with hemophilia. If selected, you will receive an incentive of \$50 for participating in the group.

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 a 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. 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]

4. Do you have a child aged 5–12 or 16–19 years living with hemophilia?

_____ No [Thank you; end call]

_____ Yes [Continue]

5. If the parent responds “Yes,” ask for specific age of the child(ren):

_____ Age

_____ Age

_____ Age

6. What type of hemophilia does your child have? [Gather the information; not an exclusive or inclusive criterion]

_____ 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 your child has? [Gather the information; not an exclusive or inclusive criterion]

_____ Mild [Continue]

_____ Moderate [Continue]

_____ Severe [Continue]

_____ Don't know [Continue]

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]
- € Some college (1–3 years toward a Bachelor's degree) [Continue]
- € College (Bachelor's degree) [Continue]
- € Advanced degree (postgraduate degree) [Continue]

We would like to invite you to participate in a telephone focus group with six to eight other parents. This telephone focus group will gather your opinions about delivering messages and information to parents of children 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 a confirmation letter. Please share with me your contact information, which will be private and not shared with anyone.

Participant 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.