

HANDI Focus Groups

Moderator's Guide—Parents of Children Aged 5–12 Years or Parents of Adolescents Aged 16–19 Years With Hemophilia

Welcome/Introduction (10 minutes)

Welcome and thank you very much for agreeing to participate in this telephone focus group. My name is _____, and my role is to guide the discussion tonight. I work for ICF Macro, a research consulting firm. I am not an expert in the topic we will be discussing. There are no right or wrong answers to the questions I'm going to ask, so please just try to relax and enjoy the discussion.

Before we start, I want to make sure that everyone has signed the consent form. *[Note to moderator: all participants must submit a signed consent form prior to beginning the group.]* I just want to go over some things mentioned in the consent form:

- Participation in this focus group is completely voluntary.
- All of your answers are confidential.
- You may choose to not answer any question.
- You will be compensated for your participation in the group.
- The group will last approximately 90 minutes.

The Centers for Disease Control and Prevention (CDC), in collaboration with the National Hemophilia Foundation (NHF), hired ICF Macro to conduct a series of focus groups with parents of children living with hemophilia. The main purpose of our discussion tonight is to get your feedback on what messages or information is important to communicate to parents of children living with hemophilia, that is, information that will help them maintain or improve their health as they become more independent and move toward adulthood. So we want to find out what messages or information parents need to help young adults make healthy decisions to manage their health and what are the most effective ways to communicate these messages.

To make our discussion more comfortable and run smoothly for everyone, we will need to follow a number of ground rules. *[Note to moderator: Read the ground rules; ask if any other ground rules are needed for everyone to feel comfortable; seek consensus.]*

- A. Everyone's input is important.
- B. Please speak one at a time.
- C. The session is being audio taped.
- D. People from CDC and NHF are on the phone as well listening to the group discussion.

- E. Please speak up clearly. *[Moderator to focus group: Remember, you are being audio taped. I may repeat what you say sometimes to make sure your opinion is captured on the tape.]*
- F. Stay focused on the question. *[Moderator to focus group: I may need to cut a discussion short because of the limited time we have, so brevity will be important.]*
- G. Share the floor space. *[Note to moderator: Invite quiet persons to share their opinions.]*
- H. It is okay to disagree with another's opinion or perspective. *[Moderator to focus group: If you dislike something or disagree with something that is said, I want to hear about it. However, please avoid debating or trying to sway the opinion of others.]*
- I. Model respect.
- J. If you have a cell phone, pager, or PDA, please turn it off or put it on silent mode.

Warm-up (15 minutes)

Let's begin by finding out a little bit about each of you. Please tell us your first name only and perhaps something interesting about yourself.

- **[For parents]** What has been the biggest difficulty (or problem) you have experienced with your child with hemophilia?
- **Moderator—Record a list of difficulties mentioned.**
Note to moderator: If respondents indicate they have NOT had difficulty (or problems), probe for the reasons they haven't.

Information Needs Related to Transition (25 minutes)

You have been asked to participate in this focus group today because CDC and NHF are interested in your opinion about helping your child with hemophilia transition from a child into a healthy and productive adult.

I am sure you have heard on the news that obesity has become a major issue among children today. If your child were obese, you would most likely want to help him or her grow into a healthy adult by eating correctly and exercising. This desire also applies to your child living with hemophilia: You want him or her to grow into a healthy adult.

Today, we're going to be talking about transition. For purposes of our group discussion, I want to give you a definition of transition. *[Note to moderator: Read definition out loud to the group.]*

Definition of transition: Transition, the passage from one life stage to another, can be more difficult for persons with a bleeding disorder. A person with a bleeding disorder experiences many transitions including accepting the bleeding disorder, caring for one's self, progressing through school and vocational/career planning, moving to an adult center, starting a family, reaching middle age, and retiring.

1. What kind of information related to transition issues do you feel you need or needed to help you take care of your child's hemophilia when he or she was 5–12 years old)? *[Note to moderator: Write down participant responses and use the list of responses as a point of reference for the next set of questions.]*

Probe: *[Note to moderator: ask participants the following probes if these issues/topics are not mentioned by participants when developing the list.]*

- Transition issues
 - o Social support
 - Friends-
 - Do you think information for your child on making friends and how to talk to their friends about their condition would have been helpful for them? Yes or no? Why or why not?
 - Bullying
 - Do you think information for your child on bullying and on how to deal with bullying would have been helpful or beneficial for them? Yes or no? Why or why not?
 - o Health and lifestyles
 - Exercise-
 - Do you think information for your child on exercising to improve their health would have been helpful or beneficial for your child? Yes or no? Why or why not?
 - Playing sports-
 - Do you think information for your child on playing sports and what sports your child could or could not play with their condition would have helped them? Yes or no? Why or why not?
 - Safety-
 - Do you think information for your child on what types of games or activities your child could play with their friends given their condition would have helped them? Yes or no? Why or why not?
 - o Educational/vocational/financial planning
 - School/ transition from elementary to middle school

- Do you think information for your child on transition from elementary to middle school would have helped them? Yes or no? Why or why not?
 - o Self-advocacy and self-esteem
 - o Sexual health
 - Dating
 - Do think information for your child on dating would be helpful or beneficial to them? Yes or no? Why or why not?
 - o Independent health care behaviors
 - o Other?
2. How did the type of information you needed about these issues change when your child became a young adult at 16–19 years old? ? *[Note to moderator: give participants the following scenario, "Let's look at where your child is now, and tell me how has the type of information that you or child need changed?]*
3. What types of information did your child need at that time? *[Note to moderator: write down the responses.]*

Probe:

- Transition issues
 - o Social support
 - o Health and lifestyles
 - Exercise
 - Do you think information on exercising and maintaining a healthy weight would be beneficial to your child?
 - Peer pressure
 - Do you think information on peer pressure would be helpful or beneficial to your child? Yes or no? Why or why not?
 - Do you think information on substance abuse would be helpful or beneficial to your child? Yes or no? Why or why not?

- o What about information on smoking and drug abuse, would this be helpful or beneficial to your child?
- o Information on dealing with peer pressure from friends to smoke or drink?
- o Educational/vocational/financial planning
 - College/university
 - Do you think information on colleges/ universities and their proximity to hemophilia treatment centers would be helpful or beneficial to your child? Yes or no? Why or why not?
 - Career planning
 - Do you think information on career choices for people with your condition would be helpful or beneficial to your child? Yes or no? Why or why not?
- o Self-advocacy and self-esteem
- o Sexual health
 - Dating
 - Do think information on dating would be helpful or beneficial to your child? Yes or no? Why or why not?
- o Independent health care behaviors
- o Other?

4. Of the things we just listed, what are the top three things you think are the most important? *[Note to moderator: Have participants prioritize the top three things, and write them down in order of preference.]*

5. What messages would be important to convey?

6. When do you think it would be important for your child to begin receiving information on transition issues?

Health Information Preference (10 minutes)

If you were able to create a *[Note to moderator: Offer several choices such as a brochure, poster, website, YouTube video, Facebook or MySpace page, or TV or radio ad]* for people with hemophilia on the issues we have discussed today, think about what you would want it to look like and what you would want it to say.

- What would this product be?

Probe:

- What would be the message?
- Would this attract young adults living with hemophilia? Why or why not?
- Do you think young adults living with hemophilia would find this information helpful? Why or why not?

Health Information Received (15 minutes)

Let's talk about health information that you perhaps have received about hemophilia.

7. Up to now, where have you gotten your information on hemophilia?

Probe:

- Friends, family, other people, organizations?
- Internet, books, magazines?
- If you searched the Internet, what would you look for? How would you look for information?

8. If someone were to give information to you personally about transition issues related to hemophilia, who would you trust to give you the most accurate, helpful information?

Probe:

- Would you trust or confide in a doctor, nurse, or health educator? Why or why not?
- Would you go to an organization such as the National Hemophilia Foundation, Hemophilia Federation of America, Hemophilia Treatment Centers, local hemophilia chapter, World Federation of Hemophilia, or pharmaceutical companies to seek information about transition issues related to hemophilia? Why or why not? Please explain.
- Would you trust information from a government agency such as the Centers for Disease Control and Prevention? Why or why not?

9. How would you prefer to learn about transition issues related to hemophilia?

Probe:

- Written materials, brochures, Web (social media such as Facebook and MySpace), TV and radio announcements, books, videos, personal education sessions, or group education sessions?

- An information session or discussion group?
- Would you call a 1–800 number if it were available? Why or why not?

False Close (10 minutes)

I want to make sure that I have asked you all the questions our client wants me to ask you. I will now ask CDC and NHF to email any follow up questions they would like me to ask the group. *[Note to moderator: Give participants a short five minute break while you wait for follow up questions from CDC or NHF.]*

Closing

Thank you for participating, we appreciate it. As a token of appreciation for your time and participation, we will be mailing your compensation. Incentives will be mailed to the address you provided us.