Hemophilia and AIDS/HIV Network for the Dissemination of Information (HANDI) Evaluation Support

Gretchen Simmons
Health Education Specialist/Technical Monitor
Telephone: 404-498-6734
Fax: 404-498-6799
E-mail: gmsimmons@cdc.gov
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Supporting Statement Section B. Statistical Design and Data Collection Procedures

Office of Management and Budget (OMB) Package Supporting Statement
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Section B.1. Respondent Universe and Sampling Methods

No statistical methods will be used to select respondents for the study. Instead, CDC proposes conducting a series of 12 focus groups. Each focus group will have an average of 9 participants, for an approximate total of 108 human subjects. There are two target audiences:

(1) Young adults aged 16–19 living with hemophilia
(2) Parents of adolescents aged 5–12 and parents of teens/young adults aged 16–19 living with hemophilia.

The focus groups will be conducted in the following four cities:

- Atlanta, GA
- Detroit, MI
- Philadelphia, PA
- San Francisco, CA

These four cities were selected by CDC and NHF on the basis of (1) the NHF chapter's interest in and resources available for recruiting members of the target audience, (2) the areas' population base, (3) proximity to the chapters, and (4) the cities' demographic characteristics in that the sites have varying degrees of urbanity and are racially/ethnically diverse.

Section B.2. Information Collection Procedures

Identification and Contacting of Participants
CDC will work through the NHF chapter in each city and use its community contacts to proactively identify participants. When a potential participant is identified, the NHF chapter will give the person a Recruitment Flyer (Attachment 12) that lists the information about the focus group. The flyer also contains a toll-free telephone number interested individuals can call to receive more information and enroll in a focus group. In addition, NHF chapters will also place flyers in NHF chapters where potential participants are likely to be present.

Upon being contacted by potential participants, an experienced focus group recruiter will use the Participant Screener and Recruitment Script. Three focus group screeners have been developed (Attachments 3, 4, and 5) to identify and enroll eligible participants who fit the following profile:

- Young adult males and females aged 16–17 living with hemophilia
- Young adult males and females aged 18–19 living with hemophilia
- Adult parents of children aged 5–12 or parents of teenagers/young adults ages 16–19 living with hemophilia

The following is a list of the characteristics of the targeted audiences for this study:

1. Parents of young children (aged 5–12) or parents of young adults (aged 16–19) living with hemophilia

General inclusion criteria

For the groups targeting parents, we will attempt to recruit:

- Adult participants who are 18 years or older.
- Participant must have a child aged 5–12 or aged 16–19 living with hemophilia.
- The group will be open to all races/ethnicities and genders.
- Participants must speak English.

Exclusion criteria
For the group targeting parents, we will exclude:

- Persons who are younger than 18 years of age.
- Parent of a child with Von Willebrand disease or other blood disorders.
- Persons who do not speak English.
- Persons who work or have someone in their immediate family who works for a market research firm, CDC, NHF, or a hemophilia research or treatment center.

2. Adolescents aged 16–19 living with hemophilia

General inclusion criteria
For the groups targeting adolescents aged 16–19 living with hemophilia, we will attempt to recruit:

- Participants between ages 16 and 19 who have been diagnosed with hemophilia type A/Factor VIII deficiency or hemophilia type B/Factor IX deficiency.
- The group will be open to all races/ethnicities and genders.
- Participants must speak English.

Exclusion criteria
For the group targeting adolescents aged 16–19 living with hemophilia, we will exclude:

- Persons younger than 16 years of age with hemophilia.
- Persons older than 19 years of age with hemophilia.
- Persons with Von Willebrand disease or other blood disorders.
- Persons who do not speak English.
- Persons who work or have someone in their immediate family who works for a market research firm, CDC, NHF, or a hemophilia research or treatment center.

The recruiter will obtain data on the participant's name, race/ethnicity, age, gender, mailing address, and phone number and determine whether he or she has participated in any focus group in the past. This information will be collected to determine eligibility in the focus group. Once a participant has been screened, if he or she is eligible, a confirmation letter will be mailed to the participant with detailed information of the date, time, and location of the focus group, along with an Informed Consent Form that a participant must sign and submit on the day of the focus group. For participants aged 16–17, permission from a parent or legal guardian must be obtained in order for that individual to participate in the focus group.

As with most focus groups, participant attrition is expected. The recruiter will enroll 8 to 10 people for each group with the expectation that an average of 9 will actually

participate. Should there be no attrition, all those enrolled will be allowed to participate in the group.

Conducting Focus Groups
Three focus groups will be conducted in each location. Focus groups will be led by two experienced moderators who have conducted numerous studies involving focus groups with parents, adolescents, and specialized populations such as people with blood disorders. The protocol is outlined in the Moderator's Guides (Attachments 6 and 7).

Content Capture
ICF Macro will take notes during each focus group using a secure laptop that can be accessed only through a unique login and password. The notes will capture the following information:

- Participant quotes
- Nonverbal cues (such as laughter, nodding, and discomfort)
- Follow-up questions

High-quality audiotape equipment will be used to ensure an accurate recording of the discussion. All audiotapes will be accurately labeled with date, time, and location, and they will be collected by the moderator at the conclusion of each focus group. The audiotapes will be in the moderator's possession or in a secure location at all times until they are sent to a transcription service firm.

When electronic transcripts are produced, they will be stripped by the transcriptionist of all references to participant identities beyond first names. Audiotapes will be maintained in a locked file cabinet for 3 years and then destroyed.

Section B.3. Methods to Maximize Response Rates

To maximize response rates, the NHF chapters in each city will assist in identifying participants by posting and distributing recruitment flyers. In addition, a professional recruitment firm will be contracted in each city to meet the target sample size. Professional agencies are able to recruit participants very efficiently and can ensure that the appropriate number of participants is available for the focus groups. Recruitment firms have been identified in each community and have been briefed on the requirements of the focus groups.

To further maximize response rates, focus groups will be held after working hours and/or on weekends in settings that allow participants to feel comfortable and to articulate their views and feelings. The market research firms in each selected city are located within close proximity to potential participants. All participants will receive a $75 incentive for participating in the focus group. Research has consistently shown the value of offering a modest remuneration for motivating respondents to participate in a research study: "Focus groups are unique from other data-gathering processes in terms of the investment that must be made by the individual. It is therefore no surprise that a tradition has been established to provide incentive for participation. From a practical aspect, it would be

next to impossible to conduct focus groups without incentives in some situations. The incentive is not a reward and not really an honorarium or salary. It is an incentive. It serves as a stimulus to attend the session. The primary function of the incentive is to get the participants to show for the focus group—and to show up on time. The incentive serves to protect the promised time slot from being preempt."[1]

The recruiting firm in each city will follow up with a reminder phone call and e-mail to each participant a few days prior to the focus group, reminding them of their participation and confirming their attendance.

Section B.4. Tests of Procedures

The Moderator's Guides for this study have not been pilot tested. However, the development of the guides was based on feedback and input received from the HANDI Evaluation Working Group. This group consisted of experts, currently working or who have experience working with adolescents with hemophilia and their parents. This group provided insight and recommendations on the development of the Moderator's Guides.

Components of the Moderator's Guides were used in a previous focus group study. Specifically, from 2007–2008, ICF Macro conducted 40 focus groups for the Florida Department of Health's Tobacco and Cessation Campaign; the purpose of these focus groups was to explore what types of messages and materials best resonate with youth aged 14–24 to prevent teens and young adults from using tobacco products. Questions from the moderator's guide used in that study have been taken to develop the questions for the proposed HANDI evaluation project. Findings from the Florida Tobacco Prevention and Cessation focus groups delivered results that helped the Florida Department of Health identify and develop messages and materials for a successful tobacco prevention and cessation campaign.

It is anticipated that participant recruitment will begin 2 to 3 weeks following OMB approval and that it will take approximately 4 weeks to recruit the full complement of participants in each site. Focus groups will be conducted 4–6 weeks after recruitment is complete. At the conclusion of all 12 focus groups, the notes and audio recordings from the focus groups will be analyzed for common themes and divergent viewpoints. The analysis will highlight common themes or concerns that emerge from the focus groups. A final report will be written that will include a discussion of the methodology used, findings, and recommendations. The analysis and report will be completed 12 weeks after the final focus group is conducted.

Section B.5. Statistical Consultants

No statistical analysis will be undertaken for this effort. Therefore, individuals were not consulted on the statistical aspects of the project.

[1] Krueger RA, Casey, MA. Focus groups. A practical guide for applied research. Thousand Oaks (CA): Sage; 2009.

The person responsible for overseeing the data collection is Mel Miller, ICF Macro; telephone: 240–747–4750; e-mail address: mary.e.miller@macrointernational.com

The person responsible for data collection and analysis is Dianne Fragueiro, ICF Macro; telephone: 240–747–4767; e-mail address: Dianne.Fragueiro@macrointernational.com