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

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Supporting Statement Section B. Statistical Design and Data Collection Procedures

Office of Management and Budget (OMB) Package Supporting Statement
Hemophilia and AIDS/HIV Network for the Dissemination of Information (HANDI) Evaluation Support
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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 telephone 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.

ICF Macro will work with CDC and NHF to identify and recruit focus group participants. The National Hemophilia Foundation (NHF) will send an e-mail blast to the approximately 6,000 people affected by bleeding disorders listed in their organization's database with information about the telephone groups and the toll-free number to call to get more information and/or find out if they qualify to participate in one of the groups. Upon reading the brief email, interested individuals can choose to call the 1-800 number provided or not. Any action taken by individuals at this point is completely voluntary.

In addition, NHF will send revised recruitment fliers and banners to each Hemophilia Treatment Center (HTC) and NHF Chapter head to post on their web site and/or Facebook page. Each HTC and chapter will assist in recruiting efforts by posting recruitment flyers where potential participants are likely to be present. The revised recruitment fliers will reflect the change from in-person focus groups to telephone groups and provide the new dates and times as well as a toll-free number prospective participants will be instructed to call if they are interested in participating. Approximately, one week after contact with the HTCs and Chapters, ICF will do a follow-up call to ensure receipt of the recruitment materials and to encourage their cooperation with the recruitment effort.

All calls to the toll-free number will be answered directly by a recruiter at Market Ease, a recruitment firm based in Chicago. All callers will be screened using the OMB-approved screening instrument and eligible callers will be assigned to focus groups on a first-come, first-served basis until all groups are filled. Given that hemophilia affects primarily males, the adolescent groups will naturally be mostly filled with male participants. However, for the parent focus groups, the Recruiting Firm, will attempt to recruit a mix of moms and dads. Eligible individuals who may not be selected for a group will be notified and asked if they may be kept on a list in case of cancellations.

The focus groups will be conducted over the telephone using a toll-free number provided to participants in advance of the groups. A professionally trained moderator will lead the group discussions over the phone. The discussions will be audiotaped and transcribed following each group.

Section B.2. Information Collection Procedures

Identification and Contacting of Participants

ICF Macro will work with CDC and NHF to identify and recruit focus group participants. The National Hemophilia Foundation (NHF) will send an e-mail blast to the approximately 6,000 people affected by bleeding disorders listed in their organization's database with information about the telephone groups and the toll-free number to call to get more information and/or find out if they qualify to participate in one of the groups. Upon reading the brief email, interested individuals can choose to call the 1-800 number provided or not. Any action taken by individuals at this point is completely voluntary.

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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:

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 and time of the focus group and instructions for dialing in, along with an Informed Consent Form that a participant must sign and return prior to 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. The recruitment firm will ask if the person would like to be mailed a consent form that would have an addressed, postage-paid return envelope for the participant to mail back the signed consent form. They will also be given the option to receive a PDF file that they could sign and send back via facsimile.

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

Twelve focus groups will be conducted over the telephone. 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
- 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, NHF will email everyone in its database (approximately 6,000 individuals who have contacted HANDI over the years to request materials and information on bleeding disorders), and request assistance from the Hemophilia Treatment Centers (HTCs) and NHF chapters in identifying participants by posting and distributing recruitment flyers and posting promotional material about the groups on their websites and facebook and twitter pages. In addition, a professional recruitment firm will be contracted 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. A recruitment firm has been identified and 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. All participants will receive a $50 incentive for participating in the focus group and, if one of the first 10 adolescent participants to have qualified, an iTunes gift card valued at $15. 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 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.

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

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 6 to 8 weeks following OMB approval. Focus groups will be conducted 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.

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