Supporting Statement B

for

Formative Research to Support the Development of Sickle Cell Disease Educational Messages and Materials for the Division of Blood Disorders

New Request

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November 17, 2011

B. Collections of Information Employing Statistical Methods

B.1. Respondent Universe and Sampling Methods

The potential respondent universe is comprised of the approximately 70,000 persons living with SCD in the United States. No statistical methods will be used to select respondents for the study. Instead, CDC proposes conducting a series of 10 focus groups. Each focus group would have up to 9 members for an approximate total of 90 human subjects. Eight in-person focus groups with people with sickle cell disesease (SCD) will be held. Participants in any focus group will all be of the same gender. Male and female in-person focus groups will be conducted with each of the following types of individuals:

(1) Adolescents aged 15-17 with sickle cell disease
(2) Young adults aged 19-25 with sickle cell disease
(3) Adults aged 26-35 with sickle cell disease
(4) Older adults aged 36 and over with sickle cell disease

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

- Atlanta, GA
- Detroit, MI
- Oakland, CA
- Philadelphia, PA

In addition, one telephone focus group with adolescents and one telephone focus group with older adults will be conducted. Participants in these focus groups will be recruited in rural areas in other parts of the country, to enable identification of the informational needs of people with SCD in rural areas in states which are not part of the Registry and Surveillance System for Hemoglobinopathies (RuSH).

B.2. Procedures for the Collection of Information

Identification and Contacting of Participants

To recruit participants with SCD for in-person focus groups, we will work closely with local chapters of the Sickle Cell Disease of America Association (SCDAA), local hospitals and community providers serving adults with SCD, Comprehensive Sickle Cell Centers (CSCCs) in Atlanta, Detroit, Oakland, and Philadelphia, and CDC partners in Registry and Surveillance System for Hemoglobinopathies (RuSH) states. For the telephone focus groups, we will work with five local chapters of SCDAA to recruit people with SCD who do not live near urban treatment epicenters. For both in-person and telephone groups, we will attempt to reach a diverse group of participants including those who may be considered hard-to-reach (e.g., do not have a phone, are less engaged in their care, are non-African-Americans).

Upon being contacted by potential participants, an experienced focus group recruiter will use the Participant Screener and Recruitment Script (Attachment 5). The screener was developed to identify and enroll eligible participants fitting the following profiles:

- Adolescent males and females aged 15-17 with sickle cell disease
- Young adult males and females aged 19-25 with sickle cell disease
- Adult males and females aged 26-35 with sickle cell disease
- Older adult males and females aged 36 and over with sickle cell disease

The table below shows provides details on the recruitment profiles for each location.

	Target Audience			
	Adolescents (ages 15–17) [3 groups]	Young Adults (ages 18–25) [2 groups]	Adults (ages 26–35) [2 groups]	Older Adults (ages 36+) [3 groups]
Atlanta (2 groups)		Females		Females
Detroit (2 groups)	Males		Males	
Oakland (2 groups)	Females		Females	
Philadelphia (2 groups)		Males		Males
Various (by telephone; 2 groups)	Females			Males

Conducting Focus Groups

Focus groups will be led by experienced moderators who have conducted numerous studies involving focus groups with adolescents and specialized populations such as people with blood disorders. The gender of the moderator and note taker will be matched to the gender of the participants. Moderators and note takers will be trained in a 1-day training session to ensure familiarity with project goals, the research protocol, SCD and its impacts, human subject issues, and procedures to deal with health-related issues and other problems that might arise. The protocol is outlined in the Moderator's Guides (Attachment 4).

The CDC does not intend to generalize beyond the specific sites and/or respondents selected. Qualitative research is a process of naturalistic inquiry that seeks in-depth understanding of social phenomena within their natural setting. It focuses on the "why" rather than the "what" of social phenomena and relies on the direct experiences of human beings as meaning-making agents in their daily lives. With this understanding qualitative methods produce a large amount of detailed information about a smaller number of people that results in rich understanding but tends to reduce generalizability.

Content Capture

AIR 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

In-person focus groups will be videotaped; telephone focus groups will be audio-taped. The recordings 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 transcripts are produced, they will be stripped by the transcriptionist of all references to participant identities beyond first names. The recordings will be provided to CDC at the end of the project. Recordings will be maintained by AIR in a locked filing cabinet until the end of the project and then destroyed.

We will not be using data to produce any parametric estimates.

B.3. Methods to Maximize Response Rates and Deal with Nonresponse

To maximize response (participation) 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. Further, locations will be selected that are accessible to participants and conducive to a free and open exchange of ideas and opinions. The location of the focus groups in each location will be decided based on the recommendation of local partners.

To further enhance response (participation) rates, each focus group participant will receive up to $75 as a token of appreciation for their interest. 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]

AIR will follow up with a reminder phone call and e-mail/letter to each participant a few days prior to the focus group, reminding them of their participation and confirming their attendance.

B.4. Tests of Procedures or Methods to be Undertaken

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 Sickle Cell Communications Working Group. This group consisted of experts in the areas of health education and communication and those currently working with, who have experience working with, who are parents of children with SCD. In addition, the group included people with SCD. This group provided insight and recommendations on the development of the Moderator's Guide as well as review of an initial draft of the Guide.

B.5. Individuals Consulted on Statistical Aspects and Individuals Collecting and/or Analyzing Data

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

The person responsible for data collection and analysis is Dr. Roger Levine, American Institutes for Research (AIR); telephone: (650) 843-8160; e-mail address: rlevine@air.org. Dr. Levine is an experienced senior researcher who has developed sampling plans and directed analyses for dozens of projects in his 26 years as a researcher at AIR.

The person responsible for overseeing the data collection is Jennifer Stephens, American Institutes for Research; telephone: (202) 403-5476; e-mail address: jstephens@air.org.

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