

Justification for the \$75 Remuneration to Participants for CDC's Division of Blood Disorders Focus Group for Persons Living with Sickle Cell Disease

We propose participant incentives in the amount of \$75 (in-person focus groups) and \$50 (telephone focus groups) based on first-hand knowledge of the difficulty recruiting this hard-to-reach population with a rare blood disorder, similar focus group projects that have been conducted with people with blood disorders and their family members, staff expertise of a well-known government contractor, standard industry practices, and in consultation with several highly-reputable recruitment firms. It is assumed that the higher \$75 incentive the in-person focus group participants will receive for participating would go toward the transportation costs for many of them to arrive at the facility, as well as any cost incurred for off-site childcare to make it possible for them to attend. Every effort is being made to utilize a focus group facility that is located close to public transportation as well. As shown by the references below, the payment of incentives can provide significant advantages to the government in terms of direct cost savings and improved data quality.

In conducting numerous studies with hard-to-reach participants, we have found that individuals with serious health conditions such as SCD and other blood disorders are less inclined to take time away from their health routines and need a larger incentive to participate. Additionally, sickle cell disease predominately affects African Americans. Previous research experience has shown that recruiting minorities for research in general can be challenging. Some of these challenges include issues with transportation, work-related and family responsibilities, fear and/or suspicion of research institutions and their motives, lack of interest, cultural factors, influence of family members, emotional stress and inconvenience. Moreover, a major target audience for the study is teens and adolescents. Teens and adolescents are even harder to recruit because of their preoccupation with their transitional years. It is our belief, given the hard-to-reach nature of the population we seek to recruit for this project, that without a high enough incentive we will fail to recruit an adequate number of participants into the focus groups resulting in the inability to identify themes in the data or draw any valid or reliable conclusions.

A sampling of focus group projects with participants affected by a blood disorder that have required us to use at least a \$75 incentive follows:

- (1) The American Thrombosis and Hemostasis Network (ATHN) contracted with RTI International to conduct a formative evaluation among adults and parents of children affected by bleeding disorders to assess the perceived utility of, and obtain feedback on, two patient focused technology tools: 1) ATHNready: Personal Health Report of core medical information delivered to patients and parents on a portable, wallet-sized USB flash drive; and 2) the interactive, web-based ATHNready HTC Finder. Between April and June 2009, two focus groups with adults with a bleeding disorder and three focus groups with parents of children with a bleeding disorder were conducted. Participants received a \$75 incentive to participate in the groups. Twenty-eight individuals participated in the discussions (12 patients and 16 parents).

- (2) The Cooley's Anemia Foundation, with support from the Centers for Disease Control and Prevention (CDC), contracted with Macro International, Inc. (Macro) in October 2008 to conduct a formative evaluation to better understand the barriers and facilitators that affect patients' adherence to their prescribed treatment regimens. All patients and caretakers who participated in telephone focus groups or individual in-depth interviews between January and March 2009 received a \$75 VISA gift card as an incentive to participate in the evaluation.
- (3) At a summer camp, Camp Sunshine, in Maine, ICF Macro under contract to the Division of Blood Disorders, CDC, conducted in-person focus groups with persons with Diamond Blackfan Anemia, parents of persons with Diamond Blackfan Anemia, and physicians treating persons with Diamond Blackfan Anemia. The incentive was \$100 for participation at the camp.

The following are some comments collected from a few ICF project directors drawing on their experience in planning and conducting focus groups with various, hard-to-reach populations.

Depending on the difficulty we or the recruitment firm think we'll have getting participants, we have typically offered \$75 to \$100 for 2 hours and have gone as high as \$150 for tax professionals. These are for in-person focus groups. For telephone focus groups we often offer \$50 for a 1 to 1.5 hour session.

For a very specific population, especially if it is in a large metro area, \$75 is our standard for a 90-120 minute in-person group.

We've found a larger incentive helps recruitment. When incentives are too low, it's harder or sometimes impossible to recruit certain types of participants.

When parents are expected to transport children, we've had to go with a higher incentive.

For OMB's additional consideration, we also note the following references by some subject-matter experts in published books on focus group research.

Morgan, D.L. (1997). Planning Focus Groups.

Recruiting

When you do pay stipends to participants, they can range from \$20 to \$50 for members of the general population, and much higher for more specialized samples. In general, the harder you have to look to recruit actual participants for your groups, the more attractive your offer needs to be. Are the desired participants hard to locate? Will they have time available? Are they likely to turn you down without some added incentive?

Krueger, R.A. and Casey, M.A. (2008). Focus Groups: A Practical Guide for Applied Research.

Money as an Incentive

When considering the amount of payment, the researcher risks insulting the participants with an incentive that is too small. While each person will vary, often promises of \$10 to \$20 may be too low and be a detriment to the project. When time and travel are considered, it may be below the minimum wage and just not enough to be taken seriously.

Generally, as the incentive approaches the ceiling, the time needed to recruit is reduced. In some studies, it may be more efficient to pay more for incentives and thereby reduce the recruiting time and increase the likelihood that people will show up. At the time of writing, amounts of \$50 to \$75 usually work for public and nonprofit studies.

When asked why they participate in focus groups, 66 percent of those surveyed indicated compensation as the main motivator, based on a study by Rodgers Marketing Research in Canton, Ohio (“Money not the only motivation,” 1991, p. 17).