Change Request

Women's Health Needs Study: The Health of US-Resident Women from Countries with Prevalent Female Genital Mutilation/Cutting (FGM/C)

(OMB Control No. 0920-1264 expires 05/31/2022) December 31, 2019

Summary

We request OMB approval to increase the value of the reimbursement given to women who participate in the Women's Health Needs Study as a means to improve participation. Specifically, we propose to increase the reimbursement from \$20 to \$25 per woman who initiate their interview. Participants (seed respondents) are also reimbursed for successful recruitment of women they know (second-stage respondents) to participate in the interview. We propose that reimbursement to seed respondents be increased from \$5 to \$10 for each second-stage respondent they recruit, up to a maximum of 3 second stage respondents. As a result of these changes, the total potential reimbursement would increase from \$35 to \$55.

Background and Justification

CDC is currently approved to collect information to assess the health characteristics, experiences, and needs of women living in the United States who have experienced Female Genital Mutilation/Cutting (FGM/C) or may be at risk for FGM/C because they or their mothers were born in a country where FGM/C is prevalent. Data from this study will be used to: identify public health needs of women and communities in the United States affected by FGM/C; formulate public health strategies for meeting identified needs; and inform efforts to prevent continuation of the practice of FGM/C on women who may be at risk. The Women's Health Needs Study (WHNS) will use a combined venue-based and respondent-driven sampling method that has proven effective among hard-to-reach populations.[1] Using this method, participant recruitment will begin with initial "seed" respondents who will be asked to help recruit additional eligible "second-stage" participants. Eligible respondents who consent to participate will complete a one-time, face-to-face interview using a standardized questionnaire. The study population includes US resident women aged 18 to 49 years who were born, or whose mother was born, in a country where FGM/C is prevalent.

The pilot study, which was concluded on November 8, 2019, offered \$20 to seed respondents and an additional \$5 to seed respondents for each second-stage respondents they recruited (up to a maximum of 3), for a total of \$35 maximum per respondent. As described below, the pilot study documented a need to increase reimbursements. Additionally, prospective site coordinators for the full study have expressed concern that the pilot reimbursement levels are too low given the cost of living in the six metropolitan areas under consideration for the full study.

Evidence supporting need to increase both seed and second stage reimbursement amounts:

1) The pilot study was conducted in the Atlanta metropolitan area. The future full WHNS study sites will be in cities with higher cost of living than Atlanta (e.g., New York, New York; Washington, DC; Seattle, WA), and potential collaborators in these cities have expressed concern that the current reimbursement amounts could negatively affect participation rates in their locations. They report that similar studies in their communities have offered \$50 per survey respondent in order to obtain adequate participation rates and sample sizes within study timeframes. In a December 18-20, 2019 site visit to a potential collaborating organization in the New York City area, the potential site study coordinator who heads a social services organization for African immigrants stated that the current reimbursements would not adequately compensate participants in the New York City area. Over the seven-week pilot period, study field staff reported receiving comments that the reimbursement for the seed interview were too low.

Evidence specific to the need to increase second-stage reimbursement amounts:

- 1) 50 pilot interviews were completed in the first 3.5 weeks of the seven-week pilot data collection. Of these 50, only nine (18 percent) were second-stage respondents, indicating slow second-stage recruitment.
- 2) At the conclusion of the pilot, fewer than half of the 101 completed pilot interviews (48.5%) were second-stage respondents. However, we anticipated that approximately 60% of completed interviews would come from second stage respondents. Seed respondent recruitment is costlier than second-stage recruitment and so lower levels of second-stage recruitment is likely to drive up study costs. For seed respondent recruitment, WHNS project staff are posted in venues during established time windows to recruit and screen potentially eligible respondents. In comparison, second-stage respondents are recruited and referred by seed respondents, requiring no WHNS project staff time, and are more likely to be eligible. In the pilot study, of 233 women screened, 106 were eligible and consented to participate in WHNS (45%); of 51 second-stage referrals, all were eligible and 50 (98%) of the second-stage referrals consented and completed the WHNS.
- 3) In the pilot, 26 of 51 seed respondents successfully recruited one or more second-stage respondents. Of the 26 who were eligible to receive reimbursement for having recruited second-stage respondents, 2 individuals redeemed the reimbursement. Since no Personally Identifiable Information is collected in this study due to the sensitivity of the topic, the onus for redemption of referral reimbursements is entirely on the seed respondent. One possible explanation for low redemption is that the costs associated with redeeming the reimbursement (e.g., transportation, time) were greater than the \$5 reimbursement.
- 4) Over the seven-week pilot period, study field staff reported receiving comments from some respondents that the reimbursements for both completing the seed interview and for referring second-stage participants were too low or were discouraging. Nine women specifically

mentioned that the \$5 referral reimbursement payment is not enough to convince them to recruit second-stage participants.

Because of these experiences from the pilot and the study planning meetings, we request to increase the value of the reimbursement to seed respondents from \$20 to \$25. Because second-stage recruitment was lower than anticipated, we request to increase reimbursement for successful recruitment of each of up to 3 second-stage respondents from \$5 to \$10, allowing a respondent who completes the survey and successfully recruits 3 second stage-respondents to be reimbursed a maximum of \$55. Studies that examined the effectiveness of monetary reimbursements on survey response rates found that they were effective at increasing response rates.[2-5]

Examination of the Effect of the Change in Monetary Value

If approved, we plan to examine the following evaluation questions: (1) did increasing the value of the reimbursement amounts improve second-stage recruitment, (2) did more participants who were eligible for reimbursement for second stage referrals collect that reimbursement.

To assess the first question, did increasing the value of the reimbursement amounts improve slow second-stage recruitment, we will compare the proportion of second stage respondents in the pilot after 3.5 weeks of fieldwork (\$5 reimbursements for successful recruitment of second stage respondents) with the proportion of second stage respondents after 3.5 weeks once reimbursements are increased (\$10 per second stage recruitment) in the first study site (data collection is planned to be implemented from May to July 2020).

To assess the second question, did more participants who were eligible for reimbursement for second stage referrals collect that reimbursement, we will compare the proportion of eligible seed respondents from the pilot who redeemed their reimbursement with the proportion of eligible seed respondents in the first study site who collect their reimbursements.

If the change request is approved, we will also continue to to monitor comments and concerns of study site collaborators regarding reimbursements.

Burden Estimate

No change to the burden estimate is requested.

Effect of Proposed Changes on Currently Approved Instruments and Attachments

None. The requested change does not affect any other component of the information collection.

OMB approval is requested, effective immediately.

- 1. Muhib FB, Lin LS, Stueve A, et al. A venue-based method for sampling hard-to-reach populations. Public Health Rep. 2001; 116 (supp 1):216–22. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1913675/pdf/pubhealthrep00206-0218.pdf
- 2. David, M.C. and R.S. Ware, Meta-analysis of randomized controlled trials supports the use of incentives for inducing response to electronic health surveys. J Clin Epidemiol, 2014. **67**(11): p. 1210-21.
- 3. Yu, S., et al., The effectiveness of a monetary incentive offer on survey response rates and response completeness in a longitudinal study. BMC Med Res Methodol, 2017. **17**(1): p. 77.
- 4. Abreu, D.A. and F. Winters. Using monetary incentives to reduce attrition in the survey i foncime and program participation. in Proceedings of the Survey Research Methods Section of the American Statistical Association. 1999.
- 5. Singer, E. and C. Ye, The use and effects of incentives in surveys. Annals of the American Academy of Political and Social Science, 2012. **645**(1): p. 112-141.