

Supporting Statement B for

***Palliative Care: Conversations Matter*[®] Phase Two Evaluation (NINR)**

OMB#: 0925-0683, Expiration Date: 10/31/2016

Date: September 13, 2016

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Attachment 1: Survey – Microsoft Word version

Attachment 2: Screenshots of survey

Attachment 3: Correspondence for survey – Email invitation with survey link

Attachment 4: Correspondence for survey – Reminder email

Attachment 5: Documentation from the NIH Office of Human Subjects Research Protections

B. COLLECTIONS OF INFORMATION EMPLOYING STATISTICAL METHODS

This supporting statement addresses data collection procedures related to the National Institute of Nursing Research (NINR) *Palliative Care: Conversations Matter*® Phase Two Evaluation. This section will describe in detail the various aspects of the questionnaire data collection methods.

B.1 Respondent Universe and Sampling Methods

The data collected under the National Institute of Nursing Research (NINR) *Palliative Care: Conversations Matter*® Phase Two Evaluation will rely on non-probability samples and therefore will be considered descriptive and will not be generalized to broader populations.

The potential survey respondents will be recruited from a commercially available opt-in online panel provider that maintains opt-in panels of respondents for online surveys. All panel providers considered for this study must have identity verification procedures assuring that a panel member represents a unique household. Upon joining a panel, panel members complete a demographic and psycho-social profile (i.e., age, gender, zip code of residence, employment status, and so forth). This information is periodically updated.

A non-probability sample will be used to recruit participants and will be obtained from an online panel provider. Based on the demographic profile of panelists, the panel provider will send an email invitation targeting their panel members who are parents with children under age 18. The email will inform the individuals about the survey and about the importance of their participation. In addition, the email will state that the survey is being conducted by NINR and will inform readers of the purpose and importance of the questionnaire, the confidentiality of the data, the procedures for maintaining the privacy of respondents, and that responses are voluntary. The email will also include a URL link to a secure website and a unique login code which individuals can use to complete the screener and the survey anonymously.

NINR believes that the incidence of parents and caregivers that meet the eligibility criteria for the survey (having a child with a serious illness) is only about 5% of the total U.S. adult population who have children under the age of 18. Furthermore, NINR anticipates that among respondents that successfully complete the screening criteria for the survey, a response rate of 30% is expected. This response rate is expected because of the time limitations of the audience (parents dealing with the serious illness of a child). The use of a non-probability sample will provide an efficient and cost-effective way to reach and learn about this unique population.

B.2 Procedures for the Collection of Information

The panel provider will send email invitations (see Attachment 3) to a sample of panel members that are parents or caregivers of a child/children under age 18. These panel members will be directed to a link with the screener questions to determine whether they are eligible to continue into the survey. Parents and caregivers of a child with a serious illness that is not listed among the set response categories in the screener will be held for review and then e-mailed a link to enter into the survey if deemed eligible. Data collection will be conducted online. The survey will be programmed to include relevant skips. The survey platform will allow the participants to return to survey if they did not complete it for any reason and start where they left off. Participants will submit the surveys by clicking on a submit button at the end of the survey. All questions on the survey will have an option not to provide information (or be left blank).

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

To maximize response rates, reminder emails will be sent to all non-respondents (see Attachment 4). The first reminder will be sent five days after the start of the survey (defined as the date when invitations to the survey go out) and the second reminder (if necessary) will be sent 10 days after the start of the survey. All reminders will have a link to the survey. Reminders to participants will reiterate the importance of this study and the confidentiality of responses.

A customary element of panel management is to offer those who complete surveys a certain number of points. Over time, panel members have the opportunity to turn in these points for small prizes. Individuals who respond to this survey will receive a number of points identified by the panel provider that panel members typically receive for a survey of a similar length and incidence, which will further incentivize participation and maximize response rates.

B.4 Test of Procedures or Methods to be Undertaken

Screenshots of the programmed survey can be found in Attachment 2. In addition to testing the programming of the survey, a soft launch of the survey will be conducted with about 5% of the sample. The soft launch will allow NINR to assess assumptions about the time needed to complete the survey, test the programmed skip patterns, data capture systems, and note any peculiarities in how respondents answer questions. Specifically, NINR will look for frequencies of missing or do not know/not-applicable responses.

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

Jo-Ann Kriebel

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Ms. Kriebel will be responsible for managing the project.

Diana Finegold

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Ms. Finegold will be responsible for the survey instrument design and data analysis to achieve goals of NINR.

Jon Kulok

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Mr. Kulok is responsible for the design of the data collection plan, overseeing sampling and data collection protocols.

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Ms. Sanders is responsible for providing consultation into survey instrument design and data collection plan and managing field data collection.

All data collection and analysis will be performed in compliance with Office of Management and Budget, Privacy Act, and Protection of Human Subjects requirements. The NINR project officer for the *Palliative Care: Conversations Matter* Evaluation is Ms. Jo-Ann Kriebel (office telephone: 301-496-1588; email: JoAnn.Kriebel@nih.gov).