

Supporting Statement B for

Pediatric Palliative Care Campaign Pilot Survey (NINR)

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LIST OF ATTACHMENTS

ATTACHMENT 1: SURVEY – MICROSOFT WORD VERSION

ATTACHMENT 2: SURVEY - SCREENSHOTS

ATTACHMENT 3: CORRESPONDENCE (EMAIL INVITATION, EMAIL WITH SURVEY LINK, AND REMINDER EMAIL)

ATTACHMENT 4: EXAMPLE OF CAMPAIGN MATERIALS – INTERACTIVE WORKSHEET/TEAR-OFF PAD

ATTACHMENT 5: DOCUMENTATION FROM THE NIH OFFICE OF HUMAN SUBJECTS RESEARCH PROTECTIONS

ATTACHMENT 6: NIH PRIVACY OFFICER MEMO

ATTACHMENT 7: INFORMED CONSENT

B. COLLECTIONS OF INFORMATION EMPLOYING STATISTICAL METHODS

This supporting statement addresses data collection procedures related to the National Institute of Nursing Research (NINR) Pediatric Palliative Care Campaign Pilot Survey. This section will describe in detail the various aspects of the questionnaire data collection methods.

B.1 Respondent Universe and Sampling Methods

Data will be collected from health care providers participating in the Pediatric Palliative Care Campaign pilot (hereafter referred to as pilot participants). The potential survey respondents are health care providers from two pilot sites who have agreed to participate in this pilot campaign.

This web-based survey is voluntary. A response rate of 80 percent is expected because the health care providers at the pilot sites have agreed to participate in this campaign. Fifty participants across two pilot sites (25 participants from each site) are participating in this pilot campaign. All pilot participants will be invited to take the survey.

B.2 Procedures for the Collection of Information

a. Rationale for Surveying All Respondents of a Given Type

Fifty health care providers at two pilot sites have agreed to participate in the pilot campaign. Given the small number, surveying all pilot campaign participants is indicated in order to detect variations.

b. Survey Procedures

Survey deployment and submission will be automated using an online, web-based electronic tool to collect information.

Personal identity of potential respondents will be protected by assigning a unique login code (i.e. ID number) to each response so that the respondent's email address will not be directly linked with their responses. The identity of respondents will not be released. The business email addresses of respondents will be stored separately from the questionnaire responses. All collected survey information will be analyzed and reported in aggregate.

Communications with pilot participants about the survey will be conducted via email as described below.

1. An email invitation letter (see Attachment 3) will be sent by the NIH Center for Information Technology to pilot participants, using their business email address. The notification letter will inform the pilot participants about the survey and how to participate in the survey. The letter will indicate that the survey is sponsored by the National Institute of Nursing Research of the National Institutes of Health (NIH). Specifically, the letter will:

- Briefly explain the purpose of the survey.
- Inform participants that completing the survey online will on average take about 30 minutes.

- Specify that survey responses will be kept secure to the extent permitted by law. All collected information will be analyzed in aggregate.
 - Provide contact information in case respondents have any questions about the study.
 - Inform participants that they will receive a separate email that includes a URL address to the survey and a login code.
 - Be sent from an NIH project email address at NINR_Conversations@mail.nih.gov. Email replies and non-deliverable emails will be sent to this NIH email address.
 - Ms. Adrienne Burroughs, NINR Health Communications Specialist, will sign the email invitation letter.
2. An email with login information (see Attachment 3) will be sent by the NIH Center for Information Technology to pilot participants a day after the email notification letter is sent. The letter will:
- Indicate that the survey is ready to be completed.
 - Include a URL address that will take participants directly to a secure website with the questionnaire.
 - Include a unique login code for the participant.
 - Specify that the survey is voluntary.
 - Inform participants that completing the survey online will on average take about 30 minutes.
 - Specify that survey responses will be kept secure to the extent permitted by law. All collected information will be analyzed in aggregate.
 - Provide the date and time when the survey will close.
 - Be sent from an NIH project email address at NINR_Conversations@mail.nih.gov. Email replies and non-deliverable emails will be sent to this NIH email address.
 - Provide contact information if participant has questions or technical problems.
 - Ms. Adrienne Burroughs, NINR Health Communications Specialist, will sign the email invitation letter.
3. A reminder email (see Attachment 3) will be sent to non-respondents one week after the email with login information. Pilot participants will experience no burden if they choose not to respond.

Informed Consent. When potential participants access the secure, survey website, they will be routed to the informed consent form. The consent form may be found in Attachment 7. In addition to being informed about the Pediatric Palliative Care Campaign Pilot Survey and its purpose, potential respondents will be provided with details regarding their rights as participants in the study. Specifically, the consent form will:

- Describe the process to ensure privacy of the information provided by participants.

- Explain how participants' identity and anonymity will be protected.
- Explain that participation is voluntary and that respondents can stop participation at any time.
- Describe how the data collected will be protected and safeguarded.
- Provide contact information in case respondents have any questions about the study.

Potential participants will be prompted to accept or decline participation by selecting the appropriate button at the bottom of the electronic form. Only if participants click on the "Accept" button and confirm that they are at least 18 years old, will they be routed to the first question in the survey.

Survey Data Collection. Respondents will be directed to a secure, web-based questionnaire and will be assigned a login code (i.e. an ID number). The list of business email addresses, which will be used to send the invitations, will be stored separately from responses. No personally identifying information will be collected through the survey. Responses to questions will be collected in an electronic database that can be analyzed using statistical software such as Excel, SPSS, STATA, or SAS. Data files will be kept in a secure environment and no one outside of this study will have access to them.

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

Several procedures will be implemented to maximize the response rate for the Pediatric Palliative Care Campaign Pilot Survey. The survey has been designed for maximum ease of administration, and the data collection protocol has been tailored to acknowledge respondents' contributions. The presentation of the survey has also been taken into consideration so that respondents can easily recognize that it is part of the pilot campaign that they are already familiar with through the campaign materials.

An invitation email (see attachment 3) will announce the web-based survey and indicate that it is sponsored by NINR. This email will be followed by an email with survey log-in information including the URL link to the survey and a unique log-in code. A reminder email will be sent one week after the initial email asking potential respondents to complete this survey. All emails will be sent from an NIH address (i.e., NINR_Conversations@mail.nih.gov).

Online administration of the questionnaire is expected to greatly increase the ease of data collection for these busy pilot participants. The strategy for email follow-up for those who have not responded to the email request has been carefully designed. By following up, NINR will demonstrate that it is committing time and energy to obtain the most valid data possible.

Consistent with the response rate calculations approved by the American Association for Public Opinion Research (AAPOR), response rates for this study will be calculated as follows:

Although the target respondent group for this survey consists of 50 participants, the number of expected respondents is 40. The number of expected respondents – 40 participants – is based on a target response of 80 percent. This response rate is expected because potential respondents are engaged in piloting the campaign materials and have an established connection to NINR prior to the survey deployment.

B.4 Test of Procedures or Methods to be Undertaken

The Pediatric Palliative Care Campaign Pilot Survey was programmed for web-based administration by NIH Center for Information Technology staff (see Attachment 2). The survey was tested by 4 respondents to assess clarity of content, organization of questions, and time needed to take the survey. Pretest respondents looked for typos and any issues with the questions or response sets. Based on this feedback, necessary refinements were made.

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

The following individuals were consulted on the statistical aspects of the design:

- Raquel García-Pertusa, Vice President, Ogilvy Washington, 202-729-4269
- Jenna Norton, M.P.H., Senior Account Executive, Ogilvy Washington, 202-729-4043
- Heidi D’Agostino, Research & Insights team, Ogilvy, 212-880-5248

Responsibility for collecting and analyzing information obtained through the methodologies described above will rest with NINR with support from the contractor, Ogilvy Washington, and subcontractor, Ipsos. 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 Pediatric Palliative Care Campaign Pilot Survey is Ms. Adrienne Burroughs (office telephone: 301-496-0256; email: adrienne.burroughs@nih.gov). The project manager from Ogilvy Washington is Jenna Norton (office telephone: 202-729-4043; email: jenna.norton@ogilvy.com).

NINR will facilitate the online survey through the National Institute of Health’s Center for Information Technology. The Center for Information Technology will deploy the survey to respondents and maintain the responses. The data will be analyzed by Ogilvy Washington’s vendor, Ipsos.