

Bereaved Family Member Satisfaction Survey

B. COLLECTIONS OF INFORMATION EMPLOYING STATISTICAL METHODS

1. Provide a numerical estimate of the potential respondent universe and describe any sampling or other respondent selection method to be used. Data on the number of entities (e.g., households or persons) in the universe and the corresponding sample are to be provided in tabular format for the universe as a whole and for each strata. Indicate expected response rates. If this has been conducted previously include actual response rates achieved.

Census rather than sample: We have carefully considered OMB's suggestion to use a sample rather than a census approach. We acknowledge the advantages of this approach, and we believe that a sample will, ultimately, be the best way to approach nationwide data collection using this method. However, in order to use a sampling approach, we believe that we need more data regarding response rates, variability in response rates across sites and populations, and non-response bias. We believe that this feasibility pilot offers an ideal opportunity to collect these data. Therefore, although for the proposed pilot we plan to use a census method, we have taken OMB's suggestion to include as part of the pilot feasibility data to be collected in order to determine whether in fact this method is appropriate.

Surveys will be attempted for all inpatient deaths during the pilot. For fiscal year 2006, there were 23,000 inpatient deaths in the VA system. The estimated response rates for bereaved family member surveys in the literature are approximately 50%. Plans are for a phased in implementation of this survey in three VISNs (or regions) the first year and six VISNs the following year. Assuming approximately 1200 deaths per VISN, during the first year of this survey process, we approximate 3600 deaths will have an associated survey attempted with an estimated 1800 surveys completed.

2. Describe the procedures for the collection of information, including:

- **Statistical methodology for stratification and sample selection**
- **Estimation procedure**
- **Degree of accuracy needed**
- **Unusual problems requiring specialized sampling procedures**
- **Any use of less frequent than annual data collection to reduce burden**

This Bereaved Family Member Survey will be performed only once with each family of a veteran inpatient death. Implementation of the survey process will be phased-in gradually as facilities throughout regions of the country are trained in the survey process and data reporting techniques. Responses to the survey will be entered by VA employees or appropriately trained volunteers into a central data repository. Through the use of the data repository at the Philadelphia VAMC Center for Health Equity Research and Promotion, facilities across the country can enter and retrieve information via a secure web server. The survey data is stored within the VA firewall, with password protected access in a manner similar to accessing patient information across the VA system.

See comments under #3 below for details on the analysis of data and associated determination of optimal sampling method.

Accuracy of survey results is largely determined through identification of the appropriate respondent or veteran surrogate to report on the nature of care provided during the last weeks of life. As this survey will be administered only to family members of VA inpatients, the use of next of

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kin information as required at the time of admission provides an excellent reference point for directing the survey efforts. On the initial contact with the next of kin, the survey includes an opening question to identify the appropriateness of the respondent by asking “are you the best person to answer these questions and if not, who is?” This two-step approach optimizes the targeting of respondents with the most intimate knowledge of the end of life care provided and is consistent with similar survey procedures published to date.

3. Describe methods to maximize response rate and to deal with issues of non-response. The accuracy and reliability of information collected must be shown to be adequate for intended uses. For collections based on sampling, a special justification must be provided for any collection that will not yield “reliable” data that can be generalized to the universe studied.

The instructional toolkit developed by the Palliative Care Outcomes Review Team will be used by facilities in implementing the Bereaved Family Member Survey to promote uniformity of administration techniques.

Estimated 50% response rate and possible need for more aggressive recruitment: We acknowledge a 50% response rate has the potential for significant non-response bias. Therefore, we will use this feasibility pilot to examine the effectiveness of different strategies for recruitment, and to determine whether certain strategies lead to significantly higher response rates, with less non-response bias. Specifically, we will assess the impact on recruitment and non-response of a low- and high-intensity recruitment strategy. The low-intensity strategy will consist of an introductory letter followed by 3 telephone calls. The high-intensity strategy will add an additional 3 telephone call attempts and a final letter, emphasizing the importance of this survey and inviting the respondent to call to schedule an interview.

Facilities will be randomly assigned to use either the high-or low-intensity recruitment strategy and response rates and non-response bias will be evaluated as described below. (NOTE: Based on previous research, we anticipate that the inter-facility variability in response rates will be very low and that, therefore, most variability in response rates will arise at the level of individual response rates. Therefore, this “cluster” or group-randomized approach is appropriate.) Randomization will use standard random number generation software available through the VA Center for Health Equity Research and Promotion. Site randomization will be stratified by size (# of beds) in three tertiles in order to ensure even representation of small, medium, and large facilities in the two groups.

Each facility will keep a log of calls made, letters sent, and staff time required. Comparisons of response rates, bias, and staff time will be valuable in guiding the selection of an appropriate and efficient recruitment strategy.

Analysis of non-response bias: Analysis of non-response bias is an important goal of this feasibility pilot. For all sampled deaths (in this case, all deaths in a participating VA facility), we will record the following for both respondents and non-respondents:

- Facility
- Veteran ethnicity (white, non-white Hispanic, African American, Asian/Pacific Islander, Native American, other)
- Veteran age
- Veteran’s use of hospice/palliative care
- Site of death (nursing home, hospice unit, acute care ward, or intensive care unit)
- Respondent’s relationship to the veteran

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In order to assess the potential for non-response bias using a census methodology, we will first examine overall response rates, and response rates for high- and low-intensity recruitment groups. Next, we will examine response rates for the subsets of patients identified above (e.g. by facility, region, veteran ethnicity, etc), and by recruitment strategy (high- vs. low-intensity). We will also compare the respondent and non-respondent groups, using these characteristics, to identify potential non-response bias. Finally, we will use a logit model with interaction terms to detect differential effect of our two recruitment strategies (high- vs. low-intensity) on response rates. We will use these data to define the feasibility of these recruitment strategies and to design an optimal strategy that balances efficiency and effectiveness.

In examining non-response bias, we will distinguish two main reasons for non-response: respondent refusal vs. inability to contact due to inaccurate or missing next of kin data. While the former can be addressed through more aggressive recruitment, the latter will require complementary efforts (e.g. cross referencing). Therefore, we will pay particular attention to the effect of inaccurate/missing data on response rate and on non-response bias. Based on the results of this analysis, we will determine whether additional cross-referencing strategies are necessary.

4. Describe any tests of procedures or methods to be undertaken. Testing is encouraged as an effective means of refining collections to minimize burden and improve utility. Tests must be approved if they call for answers to identical questions of 10 or more individuals.

Implementation of this survey process will be phased and all testing of recruitment strategies, response rate and non-response bias are described above.

5. Provide the name and telephone number of individuals consulted on statistical aspects of the design and the name of the agency unit, contractor(s), grantee(s), or other person(s) who will actually collect and/or analyze the information for the agency.

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