JUSTIFICATION FOR BEREAVED FAMILY MEMBER SATISFACTION SURVEY VA FORM 10-21081(NR) 2900-0701

A. JUSTIFICATION

1. Explain the circumstances that make the collection of information necessary. Identify legal or administrative requirements that necessitate the collection of information.

The mission of the Veterans Health Administration (VHA) is to provide high quality care for those who have served the Nation. Title 38 U.S.C. Section 527, requires the Secretary of Veterans Affairs to evaluate programs and provision of services to beneficiaries. Additionally, Executive Order 12862, Setting Customer Service Standards, dated September 11, 1993, calls for the establishment and implementation of customer service standards, and for agencies to "survey customers to determine the kind and quality of services they want and their level of satisfaction with current services".

The death rate for Veterans will continue to grow as the number of Veterans 85 years of age and older is projected to increase by 32 percent between 2009 and 2018. This demographic trend means that, like other health care systems, the VA will face substantial challenges in providing care to Veterans near the end of life. For example, extensive data from non-VA health care systems demonstrates that physical symptoms like pain, dyspnea and nausea are common but clinicians are often unable to recognize these symptoms and manage them adequately. Other studies have found that providers do not have adequate communication with patients about their health care preferences and patients often receive aggressive life-sustaining treatment that is not consistent with their preferences. A related problem has been the high incidence of deaths in an acute care setting. As many Veterans approaching end of life may prefer a more quiet and comfortable setting than can be provided in acute care, with improved communications and availability of services much of this end of life care could be shifted to a VA hospice unit or to hospice in the Veteran's home. The VA has been and continues to be a leader among healthcare systems in the provision of hospice and palliative care. National VA initiatives have been implemented and continue to support the development and expertise of palliative care consult teams.

This peak in Veteran deaths combined with the VA's strategic plan to focus on patient/family centered care underscores the need to assess family member satisfaction with the end of life care provided in the VA. To achieve this goal, the Bereaved Family Survey (BFS) was developed and evaluated. The purpose of the BFS is to determine the level of satisfaction of family members of Veterans who have died in VA facilities. BFS results are useful in identifying opportunities and strategies for improving the delivery of end-of-life care (see #2, below). The BFS is currently in use and is an optional measure in the Network Directors' Performance Plan for FY2011 and FY2012.

Revisions: Based on comments from VA facilities, we have proposed the following minor revisions to the survey. <u>These revisions reflect changes in wording, but no change in survey length,</u> <u>burden or intent.</u>

Revision #1: VHA proposes changing the wording of the phrase "doctors and other staff" to "staff" Based on feedback from the field, and from the advisory board panel, we believe that this new wording clarifies that it is the entire interdisciplinary team that is responsible for providing care to seriously ill Veterans and their families. This modification will result in a decreased burden of 30 seconds/survey.

Revision #2: VHA proposes adding one clarifying statement as to whom the word "staff" refers to in the questions (i.e., "By staff we mean the nurses, doctors, social workers, chaplains, nursing assistants,

therapists and others who cared for your Veteran and your family in the last month of his or her life.") This modification will result in an increased burden of 30 seconds/survey.

Summary of revisions and changes in burden: Together, these revisions reflect both a decrease of 30 seconds, balanced by the addition of one 30 second statement. Therefore, these modifications will not change the average burden/respondent.

2. Indicate how, by whom, and for what purposes the information is to be used; indicate actual use the agency has made of the information received from current collection.

BFS results are reported quarterly to VISN leadership and to the Veterans Health Administration Central Office (VHACO). Data collection is ongoing, and results are being used in four ways by facility leadership, by VISN leadership, and by VHACO:

1) To identify facilities achieving high levels of satisfaction. These findings are being used to explore processes and structures of care that may contribute to higher scores.

2) To identify facilities with low satisfaction scores, to guide facility leadership in developing plans for remediation.

3) To identify processes of care (e.g. palliative care consultations) that are associated with higher levels of satisfaction. These findings are being incorporated into training for facility leadership.

4) To measure changes in satisfaction scores over time.

5) To evaluate VISN performance as part of the Network Directors Performance Plan.

3. Describe whether, and to what extent, the collection of information involves the use of automated, electronic, mechanical, or other technological collection techniques or other forms of information technology, e.g. permitting electronic submission of responses, and the basis for the decision for adopting this means of collection. Also describe any consideration of using information technology to reduce burden.

At present, there is no electronic option for collecting BFS data. The major reason up to this point has been the sensitive nature of these surveys that led to a predominantly phone administration of surveys as the data collection method. As we transition to a predominantly mailed survey, we are investigating the feasibility and potential costs and burden savings associated with a web-based option for responding to the BFS.

Responses to the survey are entered by VA employees 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.

4. Describe efforts to identify duplication. Show specifically why any similar information already available cannot be used or modified for use for the purposes described in Item 2 above.

The VA has been a leader among health systems in the application of performance measures to improve the quality of care provided. There is not, however, any performance measure other than these surveys in place to assess the quality of care provided to the substantial number of Veterans approaching end of life. This vulnerable population is often too ill to complete surveys and too

challenging to identify prospectively for participation in satisfaction surveys. Evidence supports the use of an after-death family member survey to provide feedback on the quality of end of life care provided.

To address this need for an end of life outcome measure in the VA, a national Field Advisory Council (FAC) of VA leadership, researchers, clinicians and Veteran service organizations was established in 2004. This FAC performed a review of existing measures and validated outcome measures, sought to align the goals for end of life care within VA with the VA strategic planning goals of patient-centered care and lastly, embarked on this project to implement a bereaved family member satisfaction survey. To date, the BFS remains the only validated measure of end-of-life care and one of only two Veteran-centric measures among all VA performance measures (the other being the Consumer Assessment of Healthcare Providers and Systems [CAHPS]).

5. If the collection of information impacts small businesses or other small entities, describe any methods used to minimize burden.

No small businesses or other small entities are impacted by this information collection.

6. Describe the consequences to Federal program or policy activities if the collection is not conducted or is conducted less frequently as well as any technical or legal obstacles to reducing burden.

We reduce burden by: 1) collecting BFS data only once; there is no long-term or ongoing followup; and 2) shortening the survey from its original much longer version; the current version contains 19items, 17 forced choice questions (each with 4 options) and two open-ended questions. At present we attempt to sample the entire potential respondent population. We considered attempting to reach only a random sample to decrease costs and respondent burden; however, to do so would result in very small sample sizes at many individual VA facilities, thereby creating unstable estimates of BFS scores. Similarly, we could report BFS results less frequently (they are reported quarterly).however, less frequent or delayed reporting of survey results would result in delayed action planning and less responsive implementation of quality initiatives.

7. Explain any special circumstances that would cause an information collection to be conducted more often than quarterly or require respondents to prepare written responses to a collection of information in fewer than 30 days after receipt of it; submit more than an original and two copies of any document; retain records, other than health, medical, government contract, grant-in-aid, or tax records for more than three years; in connection with a statistical survey that is not designed to produce valid and reliable results that can be generalized to the universe of study and require the use of a statistical data classification that has not been reviewed and approved by OMB.

There are no such special circumstances. Participation in the survey is voluntary.

8. a. If applicable, provide a copy and identify the date and page number of publication in the Federal Register of the sponsor's notice, required by 5 CFR 1320.8(d), soliciting comments on the information collection prior to submission to OMB. Summarize public comments received in response to that notice and describe actions taken by the sponsor in responses to these comments. Specifically address comments received on cost and hour burden.

The notice of Proposed Information Collection Activity was published in the Federal Register on (Volume 77, Number 39, pages 12109-12110). VA received one comment in response to this notice.

The comment was received April 9, 2012 by web submission. The commenter praised the Bereaved Family Survey data collection efforts. He stated that he had an idea similar to this for conducting surveys of Veterans after a compensation and pension exam for disabilities. The VHA program office did respond by thanking him and providing contact information for the Veterans Benefits Administration (VBA) Compensation and Pension Director.

b. Describe efforts to consult with persons outside the agency to obtain their views on the availability of data, frequency of collection, clarity of instructions and recordkeeping, disclosure or reporting format, and on the data elements to be recorded, disclosed or reported. Explain any circumstances which preclude consultation every three years with representatives of those from whom information is to be obtained.

The original survey instrument was reviewed by the Palliative Care Outcomes Review Team consisting of VA leaders, palliative care experts (including physicians, one of which was a psychiatrist, nurses and social workers), researchers and Veteran service officers who support these efforts to measure bereaved family members' satisfaction. There has been no "surveying" of Veteran service organizations to obtain their input, however, there has been involvement of Veteran service organizations (as part of our National Field Advisory Council for Hospice and Palliative Care) in the decision to pursue, develop and implement this needed bereaved family member satisfaction survey.

As only one survey per Veteran death is to be administered, reporting frequency is not an issue. Since the initiation of the survey broadly, feedback from multiple stakeholders, such as the Comprehensive End of Life Care Initiative's (CELC) Leadership team, health services researchers from the Center for Health Equity Research and Promotion (CHERP) input from the Performance Measure Work Group, Jim Flaherty and Jim Schaefer from the VA Office of Surveys, which direct the SHEP/CAHPS patient satisfaction survey program have been incorporated, as well as input from the palliative care program managers at each VISN and project interviewers who administer the survey and report concerns, apparent misunderstanding about specific questions or purpose Continued input from these and other experts and stakeholders will continue throughout the administration of the survey.

9. Explain any decision to provide any payment or gift to respondents, other than remuneration of contractors or grantees.

Respondents receive no remuneration. We do include a small refrigerator magnet with each survey sent as a token. The main purpose of the magnet is to provide a toll-free contact phone number for respondents should they have any questions or concerns regarding the survey, the quality of VA healthcare, or VA benefits.

10. Describe any assurance of confidentiality, to the extent permitted by law, provided to respondents and the basis for the assurance in statue, regulation, or agency policy.

Confidentiality of records (which will include Veteran and/or family member names) is maintained behind the VA firewall within the Center for Health Equity and Research at the Philadelphia VA Medical Center in a manner similar to VA research protocol and policy. The survey

results and identifiers are not part of the Veterans' medical record. Information on the form becomes part of a system of records which complies with the Privacy Act of 1974. This system is identified as "Veteran, Patient, Employee and Volunteer Research and Development Project Records-VA (34VA11)" as set forth in the Compilation of Privacy Act Issuances via online GPO access at http://www.gpoaccess.gov/privacyact/index.html.

11. Provide additional justification for any questions of a sensitive nature (Information that, with a reasonable degree of medical certainty, is likely to have a serious adverse effect on an individual's mental or physical health if revealed to him or her), such as sexual behavior and attitudes, religious beliefs, and other matters that are commonly considered private; include specific uses to be made of the information, the explanation to be given to persons from whom the information is requested, and any steps to be taken to obtain their consent.

As this survey requests information from bereaved family members, the potential for distress is possible; however, our extensive experience over 3 and a half years indicates that this is an infrequent event. For the rare family member who does experience distress that is significant enough for them to desire additional support, the respondent is immediately referred for crisis intervention if this occurs during a phone interview and for mail surveys, the respondent is provided with a toll-free number to request additional support. If additional support is requested, they will be put in contact with the appropriate resource locally (generally a counselor or social worker on the facility's palliative care consult team).

12. Estimate of the hour burden of the collection of information:

Extrapolating from our overall response rates, we anticipate a response rate of 50%. An average annual total of 22,000 people will be asked to respond to the survey with the expectation that 11,000 will actually complete the survey. Each person is expected to spend 10 minutes responding once to the survey.

Year	Universe	Response Rate	Number of Respondents	Number of Responses	Minutes/ Response	Divided by 60	Burden Hours
1	22,000	50%	11,000	11,000	10	60	1,833
2	22,000	50%	11,000	11,000	10	60	1,833
ANNUAL AVERAGE	22,000	50%	11,000	11,000	10	60	1,833

b. If this request for approval covers more than one form, provide separate hour burden estimates for each form and aggregate the hour burdens in Item 13 of OMB 83-I.

This request covers only one form.

c. Provide estimates of annual cost to respondents for the hour burdens for collections of information. The cost of contracting out or paying outside parties for information collection activities should not be included here. Instead, this cost should be included in Item 14 of the OMB 83-I.

The cost to each respondent is \$2.50 and is calculated based on the average time to complete a survey (10 minutes) at a rate of \$15/hour. Assuming a 50% response rate, the collective annual cost

for all respondents for completing these surveys is \$27,495 (1,833 burden hours X \$15 per hour for the completion of 11,000 surveys at 10 minutes per survey).

13. Provide an estimate of the total annual cost burden to respondents or recordkeepers resulting from the collection of information. (Do not include the cost of any hour burden shown in Items 12 and 14).

There are no capital, start-up, operation or maintenance costs. Cost estimates are not expected to vary widely. The only cost is that for the time of the respondent. There is no anticipated recordkeeping burden as respondents are not required to keep a copy of the survey.

14. Provide estimates of annual cost to the Federal Government. Also, provide a description of the method used to estimate cost, which should include quantification of hours, operation expenses (such as equipment, overhead, printing, and support staff), and any other expense that would not have been incurred without this collection of information. Agencies also may aggregate cost estimates from Items 12, 13, and 14 in a single table.

For FY12, we anticipate a budget of approximately \$1,000,000. These costs, itemized below, will be supported as part of the Comprehensive End of Life Care Initiative.

10 Survey Administrators @ \$60,000/year, including benefits = \$600,000 5/ 8ths Director salary support, \$60,000/year, including benefits 1 Associate Director @ \$110,000/year, including benefits 1 Project manager @ \$80,000/year, including benefits 1 Data manager @ \$80,000/year, including benefits IT equipment: \$15,000 Furniture, supplies: \$10,000 Printing and mailing costs: \$15,000

15. Explain the reason for any burden hour changes since the last submission.

The increase in total burden hours from 1650 to 1833 (averaged over 2 years) reflects an increase in use of the survey by all VISNs throughout the VA. Prior submission reflected burden based on rollout of the survey to a few VISNs initially.

16. For collections of information whose results will be published, outline plans for tabulation and publication. Address any complex analytical techniques that will be used. Provide the time schedule for the entire project, including beginning and ending dates of the collection of information, completion of report, publication dates, and other actions.

We do not plan to publish these data.

17. If seeking approval to omit the expiration date for OMB approval of the information collection, explain the reasons that display would be inappropriate.

The VA Form does not display an expiration date, and if we are required to do so it would result in unnecessary waste of existing stock of forms at each field facility and the Service and Distribution

Center every three years. It is not cost effective to VA or any one else to pay to reprint a form just to change the expiration date. Inclusion of the expiration date would place an unnecessary burden on the respondent (since they would find it necessary to obtain a newer version, while VA would have accepted the old one). VA also seeks to minimize its cost to itself of collecting, processing and using the information by not displaying the expiration date. Therefore, VA continues to seek a waiver on displaying the expiration date on the form.

18. Explain each exception to the certification statement identified in Item 19, "Certification for Paperwork Reduction Act Submissions," of OMB 83-I.

There are no exceptions.