

**JUSTIFICATION FOR AFTER-DEATH 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 will triple between the year 2000 and 2010. 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 has illuminated the need for assessing family member satisfaction with the end of life care provided in the VA. The purpose of this measurement effort is to determine the level of satisfaction of family members of veterans who have died in VA facilities. (is there more than one survey) The survey results are proving to be extremely useful in developing and evaluating ongoing improvements in the delivery of end-of-life care (see #2, below). VHA currently plans to roll the survey out to at least half of VISNs in FY09, and to all VISNs in FY10 (see #12a, below).

Revisions: Based on comments from VA facilities, we have proposed the following revisions to the survey. These revisions reflect changes in items, but no change in survey length or burden.

Revision #1: VHA proposes dropping one item that assesses the degree to which health care providers spoke in an understandable way. This item lacked clarity and proved to have undesirable ceiling effects. This omission results in a decrease in burden, on average, of 60 seconds/survey.

Revision #2: VHA proposes adding one two-part item that assesses the presence and management of PTSD-related symptoms at the end of life. This item is being added at the suggestion of the expert advisory panel that feels that this information is both valuable, and highly relevant to the VA population. Because approximately 75% of respondents do not recall PTSD-related symptoms and

JUSTIFICATION FOR 2900-0701, Continued

therefore only answer the first part of this item, the respondent burden of this additional item is 20 seconds.

Revision #3: VHA proposes changing the wording of the question that assesses whether the respondent was told what to expect when the veteran was dying to focus instead on whether the respondent had adequate warning of the veteran's death. Based on feedback from the field, and from the advisory panel, we believe that this new wording offers data that is more readily applicable to quality improvement activities. This modification will not change the overall burden of the survey.

Revision #4: VHA proposes adding two items at the request of field advisors and the expert panel. These items assess the degree to which the respondent received adequate help with VA burial benefits and survivor's benefits. This revision will result in an additional average burden of 20 seconds per question.

Summary of revisions and changes in burden: Together, these revisions reflect a decrease of 60 seconds, balanced by the addition of three 20-second items. 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.

Satisfaction survey results are reported quarterly to VISN leadership and to VACO. Data collection is ongoing, and results are being used in four ways by facility leadership, by VISN leadership, and by VACO:

- 1) Results are defining facilities that are associated with high levels of satisfaction. These findings are being used to explore processes and structures of care that may contribute to higher scores.
- 2) Results are identifying facilities with low satisfaction scores. These findings are being used to guide facility leadership in developing plans for remediation.
- 3) Results are being used 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) Results are being used to measure changes in satisfaction scores over time as the VA Comprehensive End of Life Care Initiative is rolled out. These findings provide both a baseline and evidence of impact.

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.

Improved information technology will neither decrease the burden on the public nor provide any cost benefit to the VA. Therefore, no effort has been made to meet the goal of the Government Paperwork Elimination Act. Additionally, requesting electronic submission of responses from the bereaved at their time of loss is considered inappropriate. For this reason, the survey is kept very short. 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.

JUSTIFICATION FOR 2900-0701, Continued

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 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.

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.

This bereaved family member satisfaction survey will be conducted only once after a veteran's death. The design evaluates two administration techniques (high intensity vs. low intensity recruitment of respondents) on the associated validity of the survey and the utility of centralized reporting. If shown to be effective, this project will provide for rapid cycle reporting of survey results back to participating facilities to promote action planning and improved quality of care provided. 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.

JUSTIFICATION FOR 2900-0701, Continued

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 January 5, 2009 (Volume 74, Number 2, Pages 335-336). VA received no comments in response to this notice.

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 survey instrument has been 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 ongoing 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. To address the need for consultation outside the VA, the national Field Advisory Council (FAC) of VA leadership, researchers, and clinicians included veteran service organizations' feedback. There have been no focus groups performed using the proposed interim survey. The FAC participated in the formulation of this interim survey instrument, the clarity of the instructions, the inclusion of adequate privacy protection measures and the reporting format as provided by the Center for Health Equity Research and Promotion. As only one survey per veteran death is to be administered, reporting frequency is not an issue. Ongoing involvement of the FAC and feedback from family members via participating facilities will be incorporated in to future survey administration methods. Outside consultation has also been conducted with the public through the 60- and 30-day Federal Register notices.

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

No payment or gift is provided to respondents.

10. Describe any assurance of confidentiality provided to respondents and the basis for the assurance in statute, regulation, or agency policy.

Confidentiality of records (which will include veteran and/or family member names) will be 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 will not be part of the veterans' medical record. Information on the form will become 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-

JUSTIFICATION FOR 2900-0701, Continued

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 but experience and research with similar surveys reveal this to be an infrequent event. For the rare family member who does experience distress that is significant enough for them to desire additional support, the interviewer will ask "We've talked about several things in the last few minutes that people may find are difficult for them. Some people find that it's helpful to talk to a counselor about their feelings. I'd be happy to put you in touch with a counselor if you think that would be helpful to you." When families express a desire for additional counseling, 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:

From the results of previous phone satisfaction surveys, an expected successful response rate of 50% is anticipated. An average annual total of 19,800 people will be asked to respond to the survey with the expectation that 9,900 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	14,400	50%	7,200	7,200	10	60	1,200
2	25,200	50%	12,600	12,600	10	60	2,100
ANNUAL AVERAGE	19,800	50%	9,900	9,900	10	60	1,650

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 the respondents for completing these forms is \$24,750 (1,650 burden hours x \$15 per hour).

JUSTIFICATION FOR 2900-0701, Continued

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).

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

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 FY09, we anticipate a budget of approximately \$1,278,000. These costs, itemized below, will be supported as part of the Comprehensive End of Life Care Initiative.

12 Interviewers @ \$60,000/year, including benefits = \$720,000
2 Research assistants @ \$60,000/year, including benefits = \$120,000
1 Administrator/Assistant Director @ \$100,000/year, including benefits
1 Project manager @ \$85,000/year, including benefits
1 Data manager @ \$75,000/year, including benefits
0.30 FTE Statistician: \$50,000/year, including benefits
3 8ths Director salary support, \$50,000/year, including benefits
IT equipment: \$15,000
Furniture, supplies: \$10,000

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

The increase in total burden hours from 450 to 1,650 (averaged over 2 years) reflects an increase in anticipated use of the survey by VISNs throughout the VA. Based on the survey's initial success, the Deputy Undersecretary for Health has approved and funded its use in 12 VISNs in FY09, with the goal of including all VISNs in FY10. The impact on burden hours of this increase will be offset by data showing that most surveys can be completed in only 10 minutes (rather than 15, as estimated).

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 this 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.

JUSTIFICATION FOR 2900-0701, Continued

The VA Form do 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.