

**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. Given this trend, 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 in advanced illness, but are under-recognized and inadequately managed. Other studies have found that providers often lack the time and communication skills to discuss goals of care and treatment preferences with patients and families; there is strong evidence that when providers fail to discuss goals of care with patients and families, patients often receive unwanted, 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.

The anticipated increase 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 four consecutive years since FY2011.

Revisions: To assess the quality of care in the Home Based Primary Care program, we are proposing a Form #2 of the survey. There are slight differences between Form #1 and Form #2. Form #1 will be administered to all inpatient VAMC deaths. Form #2 will be administered to all enrolled Home Based Primary Care deaths.

Difference #1: VHA proposes replacing the word “inpatient” with the phrase “Home Based Primary Care” patient in Question #6. The original question reads “From what you know about [Patient’s] time as an inpatient, how often do you think [his/her] personal care needs – such as bathing, dressing and eating meals – were taken care of as well as they should have been?” The new question would be

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“From what you know about [Patient’s] time as a Home Based Primary Care patient, how often do you think [his/her] personal care needs – such as bathing, dressing and eating meals – were taken care of as well as they should have been?”

Summary of revisions and changes in burden: Together, these differences reflects neither decrease or increase in 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 five 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) 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.

Respondents are given three options to complete the survey – paper, telephone or web-based. Responses to the survey are collected and tabulated by a vendor and sent to the PROMISE center via a secure FTP site. The web-based option was made available in Q2FY14 to increase options for a respondent and allow respondents to complete the survey at their convenience and reduce burden. Each respondent is assigned a unique password and identifier in order to complete the survey online. The 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 the BFS to assess the quality of care provided to 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. The evidence for this type of outcome is so compelling (much of it coming from our work at the VA) that CMS is going to require a bereaved family survey (CAHPS – Hospice) to be publicly reported for all hospice agencies.

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To address this need for an end of life outcome measure in the VA, a national oversight group of palliative care leaders, researchers, clinicians and community hospice providers was established. These stakeholders provided a review of existing measures and validated outcome measures to align the goals for end of life care within VA with the VA strategic planning goals of patient-centered care. This stakeholder group continues to refine and improve the interpretation of BFS results to optimize associated care as delivered by front line staff. 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 follow-up; and 2) using a short-form of the original survey which was much longer; the current version contains 19-items, 17 forced choice questions (each with 2- 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.

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The notice of Proposed Information Collection Activity was published in the Federal Register on November 25, 2014 (Volume 77, Number 39, pages 12109-12110 and Volume 77, Number 91, pages 27542-27543). VA received two comments in response to these notices.

The first 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.

The second comment from the public was in regards to sexual orientation and self-identity of relationships as part of the BFS administration. The VHA program office responded to the commentator that the relationship identified by the respondent would be accepted and not questioned.

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, the VA's Hospice and Palliative Care program office was identified as a strong practice in the area of bereaved family surveys by the Centers for Medicare and Medicaid and participated in a Technical Evaluation Panel to promote improved quality reporting on end of life care among Medicare Hospice Benefit recipients.

As only one survey per Veteran death is 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 directs the SHEP/CAHPS patient satisfaction survey program) have been incorporated, as well as input from the palliative care program managers at each VISN. Project interviewers, who administer the survey, report any ongoing concerns and continued input from stakeholders will be sought.

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

Respondents receive no remuneration.

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

Information will be kept private to the extent permitted by law (which will include Veteran

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and/or family member names). All data are 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 six years indicates that this is an infrequent event. For the rare family member who does experience marked distress, the PROMISE staff refers the respondent for crisis intervention if this occurs during a phone interview. The survey includes a toll-free number to request additional support for mail and web-based survey respondents experiencing distress. If additional support is requested, the PROMISE Center staff connects the respondent to appropriate local resource (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 approximately 54%. An average annual total of 25,000 people (18,000 for inpatient deaths and 7,000 for HBPC deaths) will be asked to respond to the survey with the expectation that approximately 13,500 will actually complete the survey. Each person is expected to spend 10 minutes responding once to the survey.

The effect of non-response bias was examined by creating a model to predict the likelihood of response based on patient and family characteristics; then this model was used to apply weights that were equivalent to the inverse of the probability of response for that individual. We found that on average, facility-level scores did not change (mean = 61% before and after weighting). However, changes in individual facility-level scores ranges from -10% to + 11%. Based on these findings, we are currently investigating whether or not to incorporate nonresponse bias weights in reported data. (Smith D, Kuzla N, Thorpe J, Scott L, Ersek N. Exploring Nonresponse Bias in the Department of Veterans Affairs' Bereaved Family Survey? Journal of Palliative Medicine 2015; DOI:10.1089/jpm.2015.0050)

The effect of non-response bias has not yet been examined in the HBPC population but is planned when sufficient data are collected.

Year	Universe	Response Rate	Number of Respondents	Number of Responses	Minutes/Response	Divided by 60	Burden Hours
1	25,000	54%	13,500	13,500	10	60	2,250
2	25,000	54%	13,500	13,500	10	60	2,250

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ANNUAL AVERAGE	25,000	54%	13,500	13,500	10	60	2,250

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.

Hour Burden estimates for Form #1

Year	Universe	Response Rate	Number of Respondents	Number of Responses	Minutes/Response	Divided by 60	Burden Hours
1	18,000	56%	10,000	10,000	10	60	1,666
2	18,000	56%	10,000	10,000	10	60	1,666
ANNUAL AVERAGE for Form #1	18,000	56%	10,000	10,000	10	60	1,667

Hour Burden Estimates for Form #2

Year	Universe	Response Rate	Number of Respondents	Number of Responses	Minutes/Response	Divided by 60	Burden Hours
1	7,000	50%	3,500	3,500	10	60	583
2	7,000	50%	3,500	3,500	10	60	583
ANNUAL AVERAGE for Form #2	7,000	50%	3,500	3,500	10	60	583

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 \$4.00 and is calculated based on the average time to complete a survey (10 minutes) at a rate of \$24/hour. Assuming a 54% response rate, the collective annual cost for all respondents for completing these surveys is \$54,000 (2,250 burden hours X \$24 per hour for the completion of 13,500 surveys at 10 minutes per survey).

Source: Dept. of Labor Statistics

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 for respondents' time. There is no anticipated recordkeeping burden as respondents are not required to keep a copy of the survey.

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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 FY15, we anticipate a budget of approximately \$885,000. These costs, itemized below, will be supported as part of the Hospice and Palliative Care Program.

3 Survey Administrators @ \$60,000/year, including benefits = \$180,000
5/8ths Director salary support, \$99,000/year, including benefits
1 Associate Director @ \$110,000/year, including benefits
3/8ths Statistician @\$75,000/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 and website administration: \$236,000

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

The increase in total burden hours from 2,250 (averaged over 2 years) reflects the expansion of the survey to HBPC decedents in all VISNs throughout the VA. Prior submission reflected burden based on survey administration only to NOKs of inpatient decedents.

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.

Secondary analyses of aggregated and de-identified data will be published in scientific journals.

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 expiration date placeholder will be included 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.