

**SUPPORTING STATEMENT**

**Part A**

MEPS Experiences with Cancer SAQ

**November 15, 2011**

Agency for Healthcare Research and Quality (AHRQ)

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## A. JUSTIFICATION

### 1. Need for Information

The mission of the Agency for Healthcare Research and Quality (AHRQ) set out in its authorizing legislation, The Healthcare Research and Quality Act of 1999 (see <http://www.ahrq.gov/hrqa99.pdf>), is to enhance the quality, appropriateness, and effectiveness of health services, and access to such services, through the establishment of a broad base of scientific research and through the promotion of improvements in clinical and health systems practices, including the prevention of diseases and other health conditions. AHRQ shall promote health care quality improvement by conducting and supporting:

1. research that develops and presents scientific evidence regarding all aspects of health care; and
2. the synthesis and dissemination of available scientific evidence for use by patients, consumers, practitioners, providers, purchasers, policy makers, and educators; and
3. initiatives to advance private and public efforts to improve health care quality.

Also, AHRQ shall conduct and support research and evaluations, and support demonstration projects, with respect to (A) the delivery of health care in inner-city areas, and in rural areas (including frontier areas); and (B) health care for priority populations, which shall include (1) low-income groups, (2) minority groups, (3) women, (4) children, (5) the elderly, and (6) individuals with special health care needs, including individuals with disabilities and individuals who need chronic care or end-of-life health care.

Furthermore, AHRQ shall conduct and support research to provide data to improve the quality of health care through the healthcare utilization and expenditure estimates. [Section 912, (b) (2) (A) (ii) (II) and (iii) (II) and (c) (1) (2) and (3) (<http://www.ahrq.gov/hrqa99b.htm>)].

The Medical Expenditure Panel Survey (MEPS) is a nationally representative survey of the civilian noninstitutionalized population of all ages in the United States that collects comprehensive data on health care and health care expenditures from all payors (including private payors, Medicaid, the VA, and out-of-pocket) over a two-year period. The MEPS has been conducted annually since 1996. The OMB Control Number for the MEPS is 0935-0118, with an expiration date of January 31<sup>st</sup>, 2013. All of the supporting documents for the MEPS can be downloaded from [http://www.reginfo.gov/public/do/PRAViewDocument?ref\\_nbr=200910-0935-001](http://www.reginfo.gov/public/do/PRAViewDocument?ref_nbr=200910-0935-001).

The purpose of this request is to integrate the new self-administered questionnaire (SAQ) entitled, “Experiences with Cancer,” (see Attachment A) into the MEPS. Once the SAQ is integrated it will be completed by MEPS participants identified as ever having cancer. The

Experiences with Cancer SAQ data will be collected in the MEPS in early 2012; it will be subsequently removed from the MEPS once the data collection phase is over. Due to the survey design, data from round 5 for panel 15 and round 3 for panel 16 will be collected in early 2012 but will be included in the data file for 2011 which is made available to public in 2013.

There are several benefits to administering this SAQ nationally as a supplement to the MEPS. First, the accompanying oversample of persons with cancer will improve the cost estimates for patients with this disease and will allow AHRQ to conduct analysis on the long term costs of cancer for survivors. Since the survey is about the lasting effects of cancer and cancer treatments on the lives of those who have been diagnosed with cancer, the data will also allow research directed at long-term consequences of cancer and overall medical expenses. Finally, this activity will allow AHRQ to examine the feasibility of using MEPS as a vehicle for in depth analysis of other specific conditions. The questionnaire is being funded by the National Cancer Institute (NCI) and was developed through a collaboration among the Centers for Disease Control and Prevention, NCI, the National Institutes of Health, AHRQ, the American Cancer Society, and the Lance Armstrong Foundation.

The work is being conducted by AHRQ through its contractor, Westat, pursuant to AHRQ's statutory authority to conduct and support research on healthcare and on systems for the delivery of such care, including the use of surveys to collect data on the cost, use and quality of such care. 42 U.S.C. 299b-2; 42 U.S.C. 299a(a)(1), (2), (3), and (8).

## **2. How, by Whom, and for What Purpose Information Will Be Used**

The information collected will be used to examine the lasting effects of cancer and cancer treatments on the lives of those who have been diagnosed with cancer. The survey will ask about the effects of cancer, its treatment, or the lasting effects of that treatment on employment, finances, health insurance coverage, and life in general. The goal of this survey is to help understand and improve the experiences of people diagnosed with cancer in the future.

MEPS respondents identified as having cancer will be given the paper questionnaire to complete themselves. If the Experiences with Cancer SAQ respondent is available at the time of the MEPS interview, we ask that he/she complete the SAQ and give it to the interviewer before she leaves the household after completing the MEPS interview. If the SAQ is not collected before the interviewer leaves the household (including those cases where the SAQ respondent is not available at the time of the MEPS interview), he/she will either arrange a time to come back to pick it up (if it is mutually convenient for the respondent and interviewer) or we ask that the SAQ be returned in a postage-paid envelope left at the household.

## **3. Use of Improved Information Technology**

Data collection will not involve the use of any information technology. Since the Experiences with Cancer SAQ must be completed by the family member identified as having cancer, and this

person may not be present at the time of the interview, a paper questionnaire is the best option for this data collection.

#### **4. Efforts to Identify Duplication**

Some of the questions included in the Experiences with Cancer SAQ have been part of other surveys, such as National Health Interview Survey, NHIS Sample adult - Cancer Control supplement, and Medical Expenditures Panel Survey (Priority Enumeration). Since all cancer survivors will have responses to the NHIS and the MEPS household surveys, information about general health, employment, health insurance, access to care, conditions, and expenditures will already be available. Additionally, for the subset of cancer survivors in the NHIS who complete the sample adult cancer control supplement (only one adult per household), detailed information about cancer screening, family history of cancer, and genetic testing will be available. By combining the data available from these sources, we will have a larger nationally representative sample which should allow us to maximize the research possibilities related to cancer survivorship. An analysis has been planned to use the available data to compare and contrast the two points in time (NHIS cancer control and MEPS SAQ).

#### **5. Involvement of Small Entities**

This data collection will not impact small entities.

#### **6. Consequences if Information Collected Less Frequently**

The questionnaire will be administered only one time to participants in round 5 for Panel 15 and in round 3 for panel 16.

#### **7. Special Circumstances**

The data collection efforts will be consistent with the guidelines at 5 CFR 1320.5(d)(2).

#### **8. Federal Register Notice and Outside Consultations**

##### ***8.a. Federal Register Notice***

As required by 5 CFR 1320.8(d), notice was published in the Federal Register on November 2<sup>nd</sup>, 2011 for 60 days (see Attachment C). No comments were received.

##### ***8.b. Outside Consultations***

Following individuals outside of AHRQ have been consulted on the design of the Experiences with Cancer SAQ:

Kathy Virgo, PhD MBA (American Cancer Society)  
Donatus Ekwueme, PhD (Centers for Disease Control and Prevention)  
Juan Rodriguez MPH (Centers for Disease Control and Prevention)  
Wendy Hicks, MS Westat, Inc.

Gordon Willis, PhD (National Cancer Institute)  
Robin Yabroff, PhD, MBA (National Cancer Institute)

### **9. Payments/Gifts to Respondents**

There will be no payments for filling out this questionnaire. We are giving Livestrong foundation bracelets to each adult responding to the survey as a small token of appreciation for completing the questionnaire.

### **10. Assurance of Confidentiality**

Individuals and organizations will be assured of the confidentiality of their replies under Section 934(c) of the Public Health Service Act, 42 USC 299c-3(c). They will be told the purposes for which the information is collected and that, in accordance with this statute, any identifiable information about them will not be used or disclosed for any other purpose. Participants will be asked to sign an informed consent form (Attachment F).

### **11. Questions of a Sensitive Nature**

All questions pertain to the effects of cancer, its treatment, or the lasting effects of that treatment on employment, finances, health insurance coverage, and life in general. No questions will be asked about sexual behavior, religious or political beliefs, substance use, social behavior, or illegal activity. The law and most individuals consider health care to be a private matter. Because cancer is a particularly emotion-laden condition and because it can affect private bodily functions, such as sex and elimination, many patients find it to be a sensitive topic; this questionnaire does not include questions about the effect of cancer on bodily functions. However, some respondents may perceive as sensitive questions about the financial impact of cancer.

### **12. Estimates of Annualized Burden Hours and Costs**

Exhibit 1 shows the estimated annualized burden hours for respondents' time to participate in this research. The Experiences with Cancer SAQ will be completed by 2,181 persons and is estimated to require 30 minutes to complete. The total annualized burden is estimated to be 1,091 hours.

Exhibit 2 shows the estimated annualized cost burden associated with respondents' time to participate in this research. The total cost burden is estimated to be \$23,293 annually.

#### **Exhibit 1: Estimated annualized burden hours**

Activity	Number of respondents	Number of responses per respondent	Hours per response	Total burden hours
Experiences with Cancer SAQ	2,181	1	30/60	1,091
Total	2,181	n/a	n/a	1,091

**Exhibit 2: Estimated annualized cost burden**

Activity	Number of respondents	Total burden hours	Average hourly wage rate*	Total cost burden
Experiences with Cancer SAQ	2,181	1,091	\$21.35	\$23,293
Total	2,181	1,091	n/a	\$23,293

\*Based on the mean average hourly rate for all occupations (00-0000), National Compensation Survey: Occupational Wages in the United States May 2010, "U.S. Department of labor, Bureau of Labor Statistics".

**13. Estimates of Annualized Respondent Capital and Maintenance Costs**

Capital and maintenance costs include the purchase of equipment, computers or computer software or services, or storage facilities for records, as a result of complying with this data collection. The only cost to the respondent will be that associated with their time to respond to the information collection, as shown in Exhibits 1 and 2.

**14. Estimates of Annualized Cost to the Government**

Exhibit 3 shows the estimated total cost for the Experiences with Cancer SAQ. Since the SAQ will only be used once in 2012 the total and annual costs are identical. The total cost is approximately \$1,050,000.

**Exhibit 3. Estimated Total and Annualized Cost**

Cost Component	Total Cost	Annualized Cost
Sampling Activities	20,000	20,000
Interviewer Recruitment and Training	0	0
Data Collection Activities	300,000	300,000
Data Processing	600,000	600,000
Production of Public Use Data Files	80,000	80,000
Project Management	50,000	50,000
<b>Total</b>	<b>1,050,000</b>	<b>1,050,000</b>

**15. Change in Burden**

The addition of the Experiences with Cancer SAQ to the MEPS will increase the total burden by 1,091 hours. This is a one-time increase for 2012 only.

## **16. Time Schedule, Publication and Analysis Plans**

The data collection is scheduled to begin in January 2012. The estimated time schedule for data collection is between February 2012 to May 2012.

Data from the questionnaire consists of questions related to Cancer history, Impact of cancer on work, caregivers, health insurance, cancer-specific access to care, effect of cancer treatment on finances and life in general.

The data will be analyzed along with rest of MEPS data to research the following questions:

- What proportion of cancer survivors report problems with access to medical care compared with individuals without cancer?
- What proportion of cancer survivors report problems with access to cancer care?
- Do problems with access to medical care change over time for cancer survivors compared with individuals without cancer?
- Is family history of cancer associated with access to medical care for cancer survivors and individuals without cancer?
- Do cancer survivors have greater health care utilization than individuals without cancer?
- Do cancer survivors have greater expenditures than individuals without cancer?

Information collected from this SAQ would be in addition to other existing publicly available data and would be beneficial for estimating the burden of cancer in the cancer survivors. Data from this effort can be used to address key gaps in cancer survivorship research and inform efforts by health care policy makers, healthcare systems, and employers to improve the cancer survivorship experience in the US.

## **17. Exemption for Display of Expiration Date**

No exemption is being requested.

### **List of Attachments**

Attachment A – Experiences with Cancer SAQ – English Version

Attachment B -- Experiences with Cancer SAQ – Spanish Version

Attachment C – Federal Register Notice