

Understanding in the Needs of Ovarian Cancer Survivors

Supporting Statement – Section B

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Program Official/Project Officer

Mary Puckett, PhD

Comprehensive Cancer Control Branch

Division of Cancer Prevention and Control

National Center for Chronic Disease Prevention and Health Promotion

4770 Buford Highway NE, MS F-76

Atlanta, GA 30341

770-488-6451

xdg6@cdc.gov

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LIST OF ATTACHMENTS

Attachment 1 – Section 301 of the Public Health Service Act

Attachment 2a– 30-Day FRN

Attachment 2b– 60-Day FRN

Attachment 3a – Mail-in Questionnaire

Attachment 3b – Web-based Questionnaire

Attachment 3c – Web-based Screener and Informed Consent only

Attachment 4a –Mailed Invitation Letter for State Cancer Registry Recruitment

Attachment 4b – Mailed Frequently Asked Question Insert for State Cancer Registry Recruitment

Attachment 4c –Mailed Initial Questionnaire Reminder for State Cancer Registry Recruitment

Attachment 4d –Mailed Final Questionnaire Reminder for State Cancer Registry Recruitment

Attachment 5- Web-based Frequently Asked Question Insert for State Cancer Registry

Attachment 6a – NORC IRB Approval Letter

Attachment 6b – CDC IRB Approval Letter

SECTION B – DATA COLLECTION PROCEDURES

B.1. Respondent Universe and Sampling Methods

Respondent Universe

The respondent universe for the “Understanding Important Issues in Ovarian Cancer Survivorship (OCS)” study is women who have been diagnosed with ovarian cancer. Women will be recruited via state cancer registries.

Sampling Methods

The overall sample design targets 1,200 completed interviews.

NORC will work with CDC to identify states to assist with this study. The states will be selected based on the accessibility of the data from their state cancer registry and the states own availability to provide assistance for data collection. NORC will reach out to the selected states to provide an overview of the study, discuss logistics, and gauge interest in assisting with recruitment efforts. NORC will work with those states who are interested and willing to identify eligible women to contact for participation.

A random sample of eligible women diagnosed 6 or more months prior to sampling will be drawn across multiple state registries, with an equal allocation of sample drawn from each participating registry. If one or more states do not have a sufficient number of eligible women for sampling purposes, the remainder of the targeted sample will be allocated to the other participating registries.

B.2. Procedures for the Collection of Information

The project will assess the needs of ovarian cancer survivors during their disease trajectory. Specifically this study seeks to: 1) describe and assess the physical and mental health of ovarian cancer survivors; 2) understand the suite of medical and non-medical interventions ovarian cancer survivors may use to manage their condition, as well as late and long-term effects; 3) explore barriers and facilitators in accessing and receiving appropriate diagnostic care, cancer treatment, and follow-up care; and 4) assess access to and utilization of cancer survivorship programs that address the varying needs (psychological, medical, informational, etc.) of ovarian cancer survivors. The data collection instrument is included in this submission as **Attachments 3a and 3b**.

B.2.1 Data Collection Procedures

Respondents will be recruited via state cancer registries.

All selected sample members from the state cancer registries will be mailed an initial invitation with a web address and unique login (**Attachment 4a**). The initial mailing will also contain a frequently asked questions document to provide additional information on the study itself (**Attachment 4b**). All surveys will include a study ID to track responses.

NORC will focus its initial contact attempts on encouraging respondents to complete the questionnaire online. However, approximately one month after the web questionnaire invitation mailing, NORC will begin implementation of a mail survey option. Eligible women who did not complete the questionnaire during the first month will be mailed a personalized self-administered questionnaire packet. Each packet will include a tailored survey, a cover letter addressed to the respondent (**Attachments 3a and 4c**), and a business reply envelope. Seven weeks after the initial questionnaire mailing, NORC will send a second hardcopy of the questionnaire to all non-responders with another personalized cover letter (**Attachment 4d**). Respondents who complete the hardcopy version of the questionnaire will be sent the \$10 Amazon gift code when their questionnaire has been received, while those who complete the web survey will be assigned a gift code automatically that can be emailed to them. The methods proposed are adapted from those outlined in Dillman's Tailored Design Method and considered best practices for multi-mode surveys (Dillman, Smyth, & Christian, 2014).

B.2.2 Estimation Procedures

Survey Weights

The major weakness in non-probability samples is the lack of representativeness of the population of interest as described in traditional sample survey methodology. Initial probabilities of selection are unknown in non-probability based samples, thus design-based inference of sample outcomes to the population of interest is not feasible

Nonprobability surveys require different approaches to weighting and estimation. Because samples are not obtained from a frame representing the population, there are no known selection probabilities. Participants are following some type of self-selection mechanism that can result in differences between the population and sample distributions that are correlated with variables of interest. In addition, coverage of the population that can choose whether to participate in the survey relative to the full population of interest, or non-response bias, cannot be determined.

If necessary, we will deal with missing values using the hot-deck imputation method. Hot deck

imputation is a cost-efficient imputation method that involves replacing the missing values for variables with the values from a respondent who answered other questions from the survey in a similar way or is alike based another metric. This is referred to as the “nearest neighbor” due to their likeness to the respondent with missing data (See Andridge and Little, 2010).

B.3. Methods to Maximize Response Rates and Deal with Nonresponse

The survey will be offered through a multi-mode approach using both computer-assisted web technology and self-administered questionnaire modalities. The following procedures will be used to maximize cooperation to achieve the desired participation rates:

- Non-respondents from the state cancer registry sample will be sent a series of mailings prompting response.
- All respondents will be offered a \$10 Amazon gift code upon completion of the survey. Research shows that incentives increase the odds of survey completion (Edwards et al., 2007).

NORC will provide a project specific email and toll-free number for respondents should they have any questions about the study. NORC will also provide the toll-free number for the NORC IRB hotline should participants have any questions about their rights as study participants.

B.4. Test of Procedures or Methods to be Undertaken

The OCS questionnaire was cognitively tested with nine (9) English-speaking ovarian cancer survivors. Four interviews were conducted in-person in Chicago; the remaining five were completed via the telephone. The cognitive testing assessed clarity, quality, and usability of the study materials, and was used as a tool to estimate time burden associated with completing the survey. Feedback from cognitive testing was incorporated into the final version of the study materials.

B.5. Individuals Consulted on Statistical Aspects and Individuals Collecting and/or Analyzing Data

Mary Puckett, PhD, of the Division of Cancer Prevention and Control, is the Principal Investigator and Technical Monitor for the study, and has overall responsibility for overseeing the design, conduct, and analysis of the study. Dr. Puckett will approve and receive all contract deliverables (telephone: 770-488-6451).

The survey instrument and sampling and data collection procedures were designed in collaboration with researchers at NORC at the University of Chicago. NORC will oversee recruitment and data collection.

Stephanie Poland, MS, MA, [312-759-4261] has overall technical and financial responsibility for the study at NORC and led the NORC effort to design this protocol. She will direct the overall data collection effort.

Other personnel from CDC and NORC involved in design of the protocol, data collection instruments, and analysis plans are:

CDC

Juan Rodriguez, MPH MS
Division of Cancer Prevention and Control
Centers for Disease Control and Prevention
fph4@cdc.gov
770-488-3086

Sun Rim
Division of Cancer Prevention and Control
Centers for Disease Control and Prevention
fsx5@cdc.gov
770-488-0261

Marie Kumerow
Division of Cancer Prevention and Control
Centers for Disease Control and Prevention
mwi8@cdc.gov
404-498-1503
NORC

Michael Stern
Fellow, Center for Excellence in Survey Research
NORC at the University of Chicago
312-357-3891
Stern-michael@norc.org

Melissa Heim Viox
Research Director II
NORC at the University of Chicago
404-240-8412
Heimviox-melissa@norc.org

Elizabeth Ormson
Statistician
NORC at the University of Chicago
404-240-8401
Ormson-elizabeth@norc.org

Outside consultants who were consulted on the data collection instrument and recruitment plans are:

Lila Rutten, PhD
Professor of Health Services Research
Mayo Clinic Cancer Center
Rutten.lila@mayo.edu
507-293-2341

Helen Parson, PhD
Director of Data Use, ResDAC
University of Minnesota
Helen.M.Parsons@gmail.com
612-227-5997