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DEPARTMENT OF HEALTH AND HUMAN SERVICES

Centers for Disease Control and Prevention

[60Day-19-19BHM; Docket No. CDC-2019-0056]

Proposed Data Collection Submitted for Public Comment and Recommendations

AGENCY: Centers for Disease Control and Prevention (CDC), Department of Health and Human Services (HHS)

ACTION: Notice with comment period

SUMMARY: The Centers for Disease Control and Prevention (CDC), as part of its continuing effort to reduce public burden and maximize the utility of government information, invites the general public and other Federal agencies to take this opportunity to comment on proposed and/or continuing information collections, as required by the Paperwork Reduction Act of 1995. This notice invites comment on a proposed information collection project titled Understanding important issues in Ovarian Cancer Survivorship (OCS) project. The OCS project aims to better understand the needs of ovarian cancer survivors and how to more effectively develop interventions targeted to this population.

DATES: Written comments must be received on or before [INSERT DATE 60 DAYS AFTER PUBLICATION DATE IN THE FEDERAL REGISTER].

ADDRESSES: You may submit comments, identified by Docket No. CDC-2019-0056 by any of the following methods:

- Federal eRulemaking Portal: Regulations.gov. Follow the instructions for submitting comments.
- Mail: Jeffrey M. Zirger, Information Collection Review Office, Centers for Disease Control and Prevention, 1600 Clifton Road, N.E., MS-D74, Atlanta, Georgia 30329.

Instructions: All submissions received must include the agency name and Docket Number. CDC will post, without change, all relevant comments to Regulations.gov.

Please note: All public comment should be submitted through the Federal eRulemaking portal (regulations.gov) or by U.S. Mail to the address listed above.

FOR FURTHER INFORMATION: To request more information on the proposed project or to obtain a copy of the information collection plan and instruments, contact Jeffrey M. Zirger, Information Collection Review Office, Centers for Disease Control and Prevention, 1600 Clifton Road, N.E., MS-D74, Atlanta, Georgia 30329; phone: 404-639-7570; E-mail: omb@cdc.gov.

SUPPLEMENTARY INFORMATION:

Under the Paperwork Reduction Act of 1995 (PRA) (44 U.S.C. 3501-3520), Federal agencies must obtain approval from the Office of Management and Budget (OMB) for each collection of information

they conduct or sponsor. In addition, the PRA also requires Federal agencies to provide a 60-day notice in the Federal Register concerning each proposed collection of information, including each new proposed collection, each proposed extension of existing collection of information, and each reinstatement of previously approved information collection before submitting the collection to OMB for approval. To comply with this requirement, we are publishing this notice of a proposed data collection as described below.

The OMB is particularly interested in comments that will help:

1. Evaluate whether the proposed collection of information is necessary for the proper performance of the functions of the agency, including whether the information will have practical utility;
2. Evaluate the accuracy of the agency's estimate of the burden of the proposed collection of information, including the validity of the methodology and assumptions used
3. Enhance the quality, utility, and clarity of the information to be collected;
4. Minimize the burden of the collection of information on those who respond, including through the use of appropriate automated, electronic, mechanical, or other technological collection techniques or other forms of information

technology, e.g., permitting electronic submissions of responses.

5. Assess information collection costs.

Proposed Project

Understanding the needs of Ovarian Cancer Survivors – New – National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), Centers for Disease Control and Prevention (CDC).

Background and Brief Description

Ovarian cancer is the ninth most common cancer and the fifth leading cause of cancer death among women in the United States. Over 20,000 women are diagnosed with ovarian cancer each year. Due to the lack of a recommended screening test, ovarian cancer is often diagnosed at late stages, leading to low five-year survival rates. While previous studies are able to identify some of the needs of ovarian cancer survivors, particularly related to physical complications and side effects, additional research is needed to further understand the experiences and needs of survivors.

The National Academies of Sciences, Engineering, and Medicine released their report, Ovarian Cancers: Evolving Paradigms in Research and Care, which identified key priorities

for researchers, including recommending research on the "supportive care needs of ovarian cancer survivors throughout the disease trajectory". In order to address these research gaps and supplement current knowledge of the ongoing needs of survivors, including how to implement programs and interventions to improve their health, CDC has supported a survey of ovarian cancer survivors.

The goal of this project is to better understand the needs of ovarian cancer survivors and how to more effectively develop interventions targeted to this population. To achieve this goal, multiple recruitment methods will be utilized to recruit this unique population of women for the study. By using state cancer registries, social media advertisements, and respondent-driven sampling (RDS), the study will ensure recruitment of a diverse population of women.

This study will focus on the following research questions:

1. What physical and mental conditions do ovarian cancer survivors experience?
2. What kinds of pharmacologic and non-pharmacologic interventions do ovarian cancer survivors utilize to manage their conditions?
3. What barriers to ovarian cancer survivors have in accessing and receiving appropriate diagnostic care, treatment, and follow-up care?

4. What unmet needs do ovarian cancer survivors have?

The overall sample design targets 1,500 completed interviews. We assume that approximately 80% of completed surveys will come from more traditional sampling utilizing lists from the state cancer registries (n=1,200). The remainder of the completed interviews will come through social media outreach and respondent-driven sampling (RDS) methods (n=300). This is a one year data collection period.

For the social media recruitment, individuals will be recruited to participate in the web survey through advertisements posted on social media sites. These ads are targeted toward the specific population of women we wish to complete the survey. Interested respondents who click on an ad will be routed to the survey landing page which will explain the purpose of the study and include consent language. If the respondent is eligible, she will complete the same survey as those recruited via the state cancer registries.

Each recruitment method (registry based or social media based) will have an opportunity to recruit other women into the study through respondent-driven sampling (RDS). We anticipate that the majority of completed interviews will be obtained through traditional sampling practices, RDS provides an

efficient way to identify other potentially eligible respondents through a networked-based recruitment approach.

Participation is voluntary. There are no costs to respondents other than their time. The total estimated annual burden hours are 1,253.

Estimated Annualized Burden Hours

Type of Respondents	Form Name	No. of Respondents	No. of Responses per Respondent	Avg. Burden per Response (in hours)	Total Burden (in hours)
Ovarian cancer survivors—state cancer registries	Mail in or web-based questionnaire	1,200	1	50/60	1,000
Ovarian cancer survivors – social media recruitment	Web-based questionnaire	195	1	50/60	163
Ovarian cancer survivors – Respondent Driven Sampling	Web-based questionnaire	105	1	50/60	88
Ovarian cancer survivors recruited	Screener Only	100	1	2/60	3

via social medial and RDS (ineligible)					
TOTAL		1,600			1,253

Jeffrey M. Zirger,

Lead,

Information Collection Review Office,

Office of Scientific Integrity,

Office of Science,

Centers for Disease Control and Prevention.

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