**Change Request**
February 28, 2018

**Information Collection Request:** Case Investigation of Cervical Cancer (CICC) Study
(OMB No. 0920-1162, exp. 02/28/2019)

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**Summary**

CDC is currently approved to collect information from cervical cancer survivors identified by three state cancer registries funded under contract HHSD2002013M53942B / 200-2016-F-90920. The Case Investigation of Cervical Cancer Study (CICC) Study seeks to understand screening and care histories of women with invasive cervical cancer, which can be prevented by a vaccine and timely screening tests. The primary data collection includes a survey offered through paper- and phone-based options, and medical chart abstraction. The recruitment of cervical cancer survivors to the study has been challenging. The study presently has a response rate of 20% with 329 completed surveys from 1,682 eligible survivors.

In order to increase the number of cervical cancer survivors that respond to the survey, CDC requests the ability to offer a web-based survey to an convenience sample of cervical cancer survivors that will be identified through a social network of cervical cancer survivors *Cervivor* (cervivor.org).

**Background and Justification**

CDC is approved to collect the information needed to better understand the facilitators and barriers to cervical cancer screening and follow up of abnormal results (OMB No. 0920-1162, exp. 02/28/2019). This information will be used to develop interventions targeted to reach never or rarely screened women, and to understand missed opportunities for treatment of precancer.

Cervical cancer survivors are a challenging population to recruit. As noted in Supporting Statement A of the approved information collection request, The IMPACT (Improving Patient Access to Quality Cancer Treatment) study is a pilot project examining barriers in access to care, treatment, and outcomes among cancer patients in New Jersey. Compared to respondents for breast, colorectal, and prostate surveys, significantly lower response rates for cervical cancer surveys was observed during the initial recruitment period. Many cervical cancer survivors in the previous study were socioeconomically disadvantaged and younger than survivors of other cancers (mean age is 40 years old).

**Explanation of changes**

In this second change request, CDC requests the addition of a convenience sample identified through a social network of cervical cancer survivors (cervivor.org). Responses would be elicited via a web-based survey instrument placed as a link on the cervivor.org website for a period of approximately 3 months. The survey opportunity would be announced via (1) email to the survivor database (n=216), (2) a notice on cervivor.org, (3) social media on the *Cervivor* Facebook page, (4) *Cervivor* events, and (5) their monthly calls. This sample would provide access to women in a survivor network across the nation and would supplement the responses provided by the cancer registry data in three states.

- The web-based survey will use the same instrument as offered to the cancer registry sample with the addition of two questions (age at diagnosis and current age, see attachment). This information is available from cancer registries for the other sample.
- The owner of the social network welcomes the opportunity to offer the opportunity for participation in the survey to her members and has expressed full support of the study.
- The potential participants will represent convenience sample who choose to take web-based survey after reading an online open invitation.
- There will be no tracking of respondents and no incentive will be provided.
- It is estimated that approximately 100 women may complete the survey (based on personal communication with the social network owner).
- This convenience sample is being approached to supplement lower than anticipated response from the cancer registry sample. Therefore, the addition of this sample is not expected to impact the burden table.

**Request for Approval**

OMB approval is requested effective immediately after the approval of the change request.

**References:**

Herman, N., Stroup A., et al. (2017). Making an IMPACT: Optimizing Patient Recruitment in Hard to Reach Populations with NJSCR. Submitted to the North American Association of Central Cancer Registries (NAACCR) Annual Meeting, NM June 2017.