Using social media for recruitment in cancer prevention and control survey-based research

(SMFR Study)

Supporting Statement – Section A

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Table of Contents

LIST OF ATTACHMENTS

Attachment 1 – Section 301 of the Public Health Service Act

Attachment 2 – 60-Day FRN

Attachment 3 – Data Collection Forms

    Attachment 3a - General Population Survey

    Attachment 3b – Cancer Survivor Survey

    Attachment 3c – High-Risk Survey

    Attachment 3d – High-Risk Follow-Up Survey

Attachment 4 – Web Recruitment Ads

Attachment 5 – Informed Consent

    Attachment 5a – Consent & Landing Page

    Attachment 5b – Frequently Asked Questions

    Attachment 5c – Follow Up Consent & Landing Page

Attachment 6 – Screeners

    Attachment 6a – Baseline Screener

    Attachment 6b – Follow Up Screener

Attachment 7 – Email Invitation

Attachment 8 – Data Collection Screenshots

    Attachment 8a – Baseline and Follow-Up Screener Web Screenshots

    Attachment 8b – General Population Survey Web Screenshots

    Attachment 8c – Cancer Survivor Survey Web Screenshots

    Attachment 8d – High-Risk Survey Web Screenshots

    Attachment 8e – High-Risk Follow-Up Survey Web Screenshots

Attachment 9 – Human Subjects Approval

    Attachment 9a – NORC IRB Approval Renewal

    Attachment 9b – CDC IRB Reliance Letter

    Attachment 9c – CDC IRB Authorization Agreement

Attachment 10 – 60-day Federal Register Notice and Comments

    Attachment 10a – Published 60-day FRN

    Attachment 10b – Comments Received from 60-day FRN

    Attachment 10c – Response to Comments

Attachment 11 – Signed Privacy Impact Assessment

- **Goal of the study:** To conduct formative research with key populations of interest to cancer prevention and control using convenient samples recruited from the internet.

- **Intended use of the resulting data:** Survey results will aid the development of programs and resources to: 1) increase utilization of cancer screening services; 2) improve long-term survivorship after cancer; and 3) improve family communication about genetic cancer testing and risk. In addition, survey results will be used for intervention development. Results will be drafted into scientific publications and submitted to peer-reviewed journals.

- **Methods to be used to collect:** Four web-based surveys will be administered to eligible respondents recruited via targeted social media and web ads.

- **The subpopulation to be studied:** 1) Up to 500 adult women age 40 and over with limited or no family cancer history and no personal history of breast cancer; 2) Up to 750 adults who have been previously diagnosed with cancer; and 3) Up to 750 adults who have a family history of cancer and/or have had genetic testing for cancer risk.

- **How data will be analyzed:** Statistical analysis of quantitative survey data and operational or administrative data.

Section A – JUSTIFICATION

A.1.   Circumstances Making the Collection of Information Necessary

The proposed project, "Social Media for Recruitment (SMFR) Study," is a new Information Collection
Request (ICR) and Office of Management and Budget (OMB) approval is requested for one year.

The Centers for Disease Control and Prevention (CDC), Division of Cancer Prevention and Control, is
requesting OMB approval to conduct a formative study to with key populations of interest to cancer
prevention and control research using social media and web platforms for study recruitment. Surveys will
evaluate breast cancer screening and perceptions about breast cancer risk among women aged 40 and
older, common challenges and issues faced cancer survivors post-treatment, and genetic risk
communication patterns among those at high risk for cancer. The information collection for which
approval is sought is in accordance with CDC's mission to conduct, support, and promote efforts to
prevent cancer and to increase early detection of cancer, authorized by Section 301 of the Public Health
Service Act (42 U.S.C. 241). A copy of the legislation is included in **Attachment 1**.

Background

Priority Research Populations

One principal interest in cancer prevention and control is making sure **women aged 40 to 50 and older**
are screened for breast cancer through routine mammography. The U.S. Preventive Services Task Force
(USPSTF) recommend adults be screened for breastcancer (U.S. Preventive Services Task Force, Final
Recommendation, 2016; U.S. Preventive Services Task Force, Final Update, 2016; U.S. Preventive
Services Task Force, 2017). Questions around who is or isn't screened for breast cancer, the intervals at
which they are screened and facilitators and barriers to being screened, require frequent investigation to
adapt and maintain the success of public health efforts to increase screening rates. Epidemiologists,
behavioral scientists, and health services researchers often rely on survey-based research to answer these
questions. This study will recruit women aged 40 and older to assess breast cancer screening practices and
facilitators and barriers associated with screening. In addition, we will also assess beliefs associated with
risk factors for breast cancer and information seeking behavior. Our goal is to develop a better
understanding of the challenges women may face in obtaining regular mammograms, how to better
educate women about risk factors for breast cancer, and how to best present that information. We hope to

develop resources and materials for women and programs based on these results. In addition, we hope to develop manuscripts for peer-reviewed publication to inform future intervention and programmatic work.

Those who have been diagnosed with cancer (referred to as cancer survivors in this package) are also a priority research population. Multiple reports and publications have indicated that those who have been diagnosed with cancer face significant challenges and limitations in their physical, mental, and financial health (Committee on Cancer Survivorship: Improving Care and Quality of Life, 2005; Centers for Disease Control & Prevention, 2004). Their continued interactions with the health care system are essential to limit the impact of treatments and monitor potential recurrence or additional primary cancers. This study will seek to recruit cancer survivors to assess quality of life, well-being, and mental and physical health, as well as investigate factors associated with insurance, employment and financial hardship. These results will be used to develop education materials, and to inform programmatic efforts and intervention development. In addition, we hope to develop manuscripts for peer-reviewed publications.

An additional population of interest to cancer prevention and control researchers are **those who are at increased risk for cancer** due to family history and hereditary mutations. Individuals with significant histories of cancer in their family often need to be screened earlier and more frequently, and may want to pursue other risk reduction and management strategies. Communication among family members about cancer risk and genetic testing results are important to ensure all relatives at increased risk are identified and are informed about their potential risk so they can pursue appropriate prevention services. This study, divided into 2 surveys to limit length of administration in one sitting, will seek to assess factors associated with disclosing genetic testing results. These results will be used to develop educational materials and communications messaging that may be used in programmatic efforts. In addition, we plan to develop materials for use in future intervention studies that are intended to facilitate familial conversations and genetic risk. These results may yield manuscripts submitted for publication in peer-reviewed journals.

Communication About Genetic Testing

Information from genetic testing is fundamentally different from traditional medical test results in that genetic testing results are of concern not only for the individual but for his or her entire family (Wiseman, Dancyger, & Michie, 2010). For the individual considering whether and how to discuss the genetic risk of cancer with family members, there can be tensions between the perceived responsibility to inform relatives, the desire to protect relatives from unnecessary worry, and the personal desire to maintain privacy about one's health and genetic makeup (Chivers Seymour, Addington-Hall, Lucassen, & Foster,

2010; Lindenmeyer, Griffiths, & Hodson, 2011; McGivern et al., 2004). Communication of genetic risk is also influenced by family dynamics involving factors such as cultural background, emotional closeness or distance between relatives, and open or closed family communication patterns (Cheung, Olson, Yu, Han, & Beattie, 2010; Dancyger et al., 2011; Kenen, Arden-Jones, & Eeles, 2004; Peterson, 2005; Wiseman et al., 2010).

Further complicating communication about familial cancer is the complexity of genetic information itself. The difficulty in understanding and conveying genetic risk information has been shown in studies that included both the public and medical professionals (Trivers et al., 2011). A lack of awareness about genetic heritability for breast and ovarian cancer risk from the paternal side of the family has been especially well documented (Bellcross et al., 2011).

Sources of information about cancer genetics vary widely as does the accuracy and usefulness of that information. Cancer in a family member is a serious event and intra-familial communication can convey both emotional support and important risk information (Jones, Denham, & Springston, 2007). Outside the family, physicians are the most trusted source of health-related information; physicians also play an important role in promoting adherence to health behavior and treatment recommendations as well as providing appropriate referrals for specialized care (Armstrong, Toscano, Kotchko, & et al., 2015; Bradford W. Hesse, Moser, & Rutten, 2010; B. W. Hesse, Nelson, Kreps, & et al., 2005). At the individual level, information from different sources is integrated or mediated by factors such as race/ethnicity, education, age, and personal beliefs. Thus persons undergoing testing for hereditary cancer mutations such as BRCA1/2 or hereditary nonpolyposis colorectal cancer (HNPCC), also known as Lynch syndrome, face complex ethical, emotional, legal, sociocultural, and psychosocial considerations in the decision to disclose genetic information to family members, healthcare providers, and others. In recent years there has been a growing interest in the processes, psychological factors, and information needs involved in disclosure of genetic information (Bodurtha et al., 2014; de Geus et al., 2015; Hodgson et al., 2014; Tercyak et al., 2013). Recent calls for educational materials or the direct assistance of health-care providers in helping people communicate with relatives about genetic risk highlights an important unmet need (Bodurtha et al., 2014; Forrest, Delatycki, Skene, & Aitken, 2007; Metcalfe, Plumridge, Coad, Shanks, & Gill, 2011; Patenaude et al., 2013; Ratnayake et al., 2011; Sharff et al., 2012). The proposed research explores the experiences of sharing genetic information within families and the results will guide identification of communication needs and inform interventions to address those needs.

Use of Social Media

We propose recruiting our three samples from the internet, specifically through ads purchased on social media sites.

In 2012 it was estimated that 79% of Americans had access to the internet (US Census); Pew Research Center estimates that as of 2016 this number had climbed to 86% of Americans currently using the internet (Pew, Internet). While those who are lower income are generally considered to be less likely to have a computer and internet access at home, the advent and proliferation of smartphones (internet-enabled phones) has increased internet access across income groups (Pew, Mobile). It's estimated that 69% of the American public has a profile on a social media platform, such as Facebook or Twitter. Use of social networking sites is similar across racial/ethnic groups, and income and education gradients (Pew, Mobile; Pew, Social). While younger individuals are more likely to have profiles on social networking sites, adults over 50 years of age are the fastest growing segments of social media platform users (Pew, Mobile; Pew, Social).

Using social networking sites as a sampling frame for survey-based research is an innovative method of recruitment. While in its infancy, using social media for research recruitment has been done in in assortment of studies, with varying levels of success (Kapp, Peters, & Oliver, 2013; Farmer, Holt, Cook, & Hearing, 2009; Richiardi, Pivetta, & Merletti 2012; Brickman-Bhutta, 2012; Graham, Fang, Moreno, et al, 2012; Williams, Proetto, Casiano, & Franklin, 2012; Akard, Wray, & Gilmer, 2014; Ahmed, Jayasinghe, Wark, et al, 2013). Studies have used social media platforms for recruitment of adolescents, smokers, men who have sex with men, illicit drug users, those with STIs, and individuals with personality disorders (Kapp, Peters, & Oliver, 2013; Farmer, Holt, Cook, & Hearing, 2009; Richiardi, Pevetta, & Marletti 2012; Brickman-Bhutta, 2012; Graham, Fang, Moreno, et al, 2012; Williams, Proetto, Casiano, & Franklin, 2012; Akard, Wray, & Gilmer, 2014; Ahmed, Jayasinghe, Wark, et al, 2013). This has been done through placement of advertisements for study participation on Facebook, use of promoted tweets in Twitter, and ads on YouTube. There is some indication that recruiting a general population-based sample may present more challenges using a social networking site for recruitment (Kapp, Peters, & Oliver, 2013; Farmer, Holt, Cook, & Hearing, 2009) than studies with more targeted research questions and populations of interest (Richiardi, Pevetta, & Marletti 2012; Graham, Fang, Moreno, et al, 2012; Williams, Proetto, Casiano, & Franklin, 2012; Ahmed, Jayasinghe, Wark, et al, 2013).

Given the ability to create targeted ads and marketing plans through social networking sites, reaching populations of interest to cancer prevention and control research shows considerable promise (Farmer, Holt, Cook, & Hearing, 2009). Profile information can be used to target ads about research to social media users with certain characteristics. For example, Facebook allows you to target ads by age, gender,

language, country, interests, behaviors, and page "likes." To recruit cancer survivors through Facebook, ads could be targeted to those who have "liked" or "subscribed" to updates on groups or organizations for cancer survivors, such as Susan G. Komen or the Breast Cancer Survivors Network. In addition, those who list on their profile (in the "about you" sections) that they are a cancer survivor or have linked to cancer survivor resources on their feeds previously can be targeted to view ads about research studies. To recruit the high-risk populations, ads could be targeted to those who have "liked" or "subscribed" to organization such as FORCE (Facing Our Risk of Cancer Empowered) or those interested in "BRCA1/2." In addition, it could be possible to target family members of individuals with cancer for recruiting potentially high risk populations through likes and public membership in family support groups like "Breast Cancer Family, Friends, & Caregiver Support Group."

In particular, we wanted to utilize this method of recruitment to better help us find hard to read populations. Two of our populations of interest, cancer survivors and those who are high risk due to family history and genetics, are hard to study because there are no real population-based methods to recruit these populations. While cancer registries are often used to recruit cancer survivors, it is difficult to recruit survivors who are more proximal to the cancer experience because registry data usually has a two-year lag. Also, not registries collect data on genetic mutations associated with cancer predispositions. Given the varying experiences that can occur when obtaining cancer treatment and the late and long-term effects that may present, developing an understanding of the challenges cancer survivors face requires somewhat larger samples. Similarly, with the advent of direct-to-consumer genetic testing and recent press coverage associated with genetic testing (for example, the opinion piece Angelina Jolie published in the New York Times), a larger sample is also required to understand if the method of genetic testing effects knowledge or ability to have informed conversations with family. A systematic review published in 2017 indicates that the benefits of using social media platforms for recruitment methods include "reduced costs, shorter recruitment periods, better representation, and improved participant selection in young and hard to reach populations (Whitaker C, et al., 2017)."

Compared to more standard recruitment methods, using social media as a sampling frame may provide some significant advantages. Namely, recruitment through social networking websites is significantly cheaper than recruitment over more traditional means (i.e., random digit dialing, through a cancer registry, through managed care organizations, etc.). Studies have indicated that recruitment through social media can cost anywhere between $9 and $30 per completed response (Richiardi, Pevetta, & Marletti 2012; Graham, Fang, Moreno, et al, 2012; Akard, Wray, & Gilmer, 2014), compared to $36 to $62 for a random digit dial survey (Davern, McAlpine, Beebe, et al, 2010; Zeigenfuss, Burmeister, Harris, et al, 2012). In addition, data can be collected much faster than through standard methods and require less data

entry and management to build analyzable datasets (Brickman-Bhutta, 2012). However, there are also limitations. Sampling bias is a concern. It is unknown if samples recruited from social networking websites will systematically differ from those recruited through more traditional means. Also, calculating response rates is difficult because there is no preset sample frame, or denominator, although there are methods to address this limitation (Eysenbach, 2004). While there are best practices and standard methods for web survey design and administration, outlined by Dillman's Tailored Design Method, social media recruitment remains less studied (Dillman, Smyth, & Christian, 2014). Given that recruitment for research over social media is a relatively new endeavor, there are currently no standard response rate calculations for social media recruitment like those for mail or phone surveys from American Association of Public Opinion Research (AAPOR) or Council of American Survey Research Organizations (CASRO).

.Approaches to Address Knowledge Gaps and Questions

To address questions related to both the use of social media for survey recruitment and communication of genetic risk, this study will collect information from three different study populations:

- **General Population.** The first survey will target the general population, focusing on cancer screening and access to care.
- **Cancer Survivors.** The second survey will target cancer survivors and focus on general health and well-being post-treatment.
- **High-Risk Individuals.** The third and fourth surveys will target those at high risk for cancer. The third survey will focus on communication of genetic risk among family members. The fourth survey will be a follow-up with high-risk individuals who have had genetic testing and will obtain their perspectives on tools and resources for communication of family genetic cancer risk.

A.2. Purpose and Use of the Information Collection

The purpose of this one-time data collection is to achieve the following aim:

Aim 1: To develop and launch surveys with 3 populations using social media platforms for study recruitment. This will consist of using Facebook, Twitter, and Google to recruit participants from 3 groups: the general population (for cancer screening), cancer survivors, and those at high risk for cancer.. Finding specialized populations for cancer prevention and control research using social media is likely to yield a higher sample size and be more cost-effective than other methods relying on finding these persons in the general population or within a managed care organization.

11

To address this aim, we will develop and launch 4 surveys with 3 populations using social media platforms for study recruitment. Respondents will be recruited via ads posted on social media and search engine websites, from the following 3 populations: general population, cancer survivors, and individuals at high risk for cancer. Table A.2-1 presents the four surveys, respondent population of interest and eligibility, and the purpose of the survey. Various ads will be posted on Facebook, Twitter, and Google using different strategic targeting options in order to assess the effectiveness of each site, ad, and recruitment strategy. The data collection instruments are included with this submission as **Attachments 3a-3d**.

Table A.2-1

	Purpose	Eligibility
Women aged 40 and over	Breast cancer screening and perceptions on breast cancer risk factors	Women over the age of 40
Survivor	General health and well-being post-treatment	Age 18 or older with a personal history of cancer
High Risk	Risk communication among family members	Age 18 or older, and at least one of the following: • Received genetic testing results that indicated high-risk for any type of cancer, • Immediate family member diagnosed with ovarian, breast, or colorectal cancer • Been diagnosed with breast, ovarian, or colorectal cancer before age 45
High Risk Follow-Up	Perspectives on tools and resources for communication of family genetic cancer risk	Adults 18 or older who have had genetic testing and were recruited via the original high risk survey, and/or new eligible high risk respondents

Individuals meeting the age criteria who visit one of the three sites (Facebook, Twitter, Google) will be eligible to view the sample targeted ads **(Attachment 4).** Interested potential 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 **(Attachments 5a & 5c)**. To determine eligibility of interested respondents, the web survey begins with a brief screener (**Attachment 6a**). Screenshots of all web surveys as they will appear

online are included in **Attachments 8a-8e**. After screening for eligibility, the respondent will continue to the full web survey appropriate for the individual based on their responses to the screener instrument, as shown in Figure 2-1.

Figure 2-1 Survey Recruitment Process
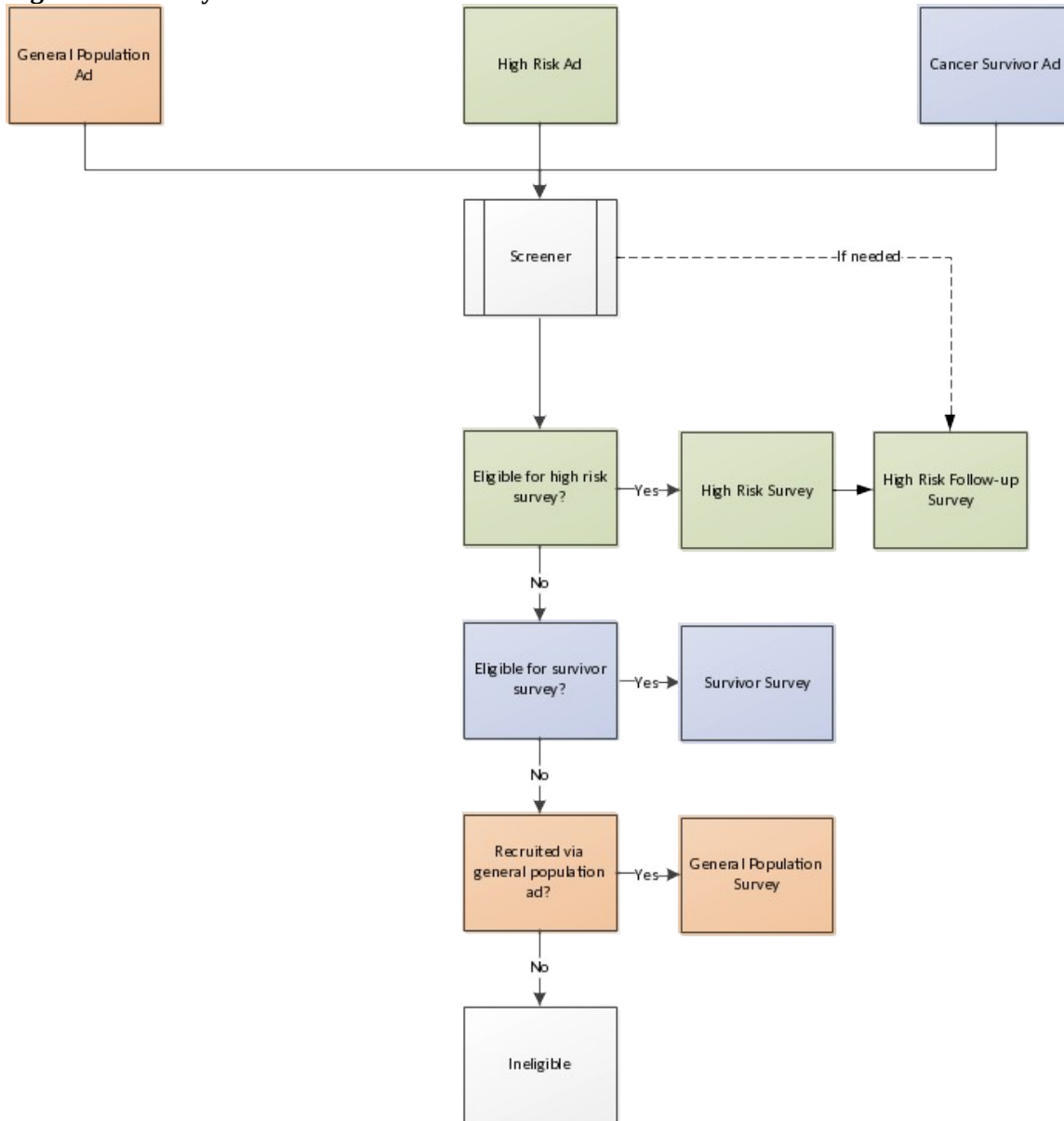
Demographic information collected from these individuals, as well as their responses to key indicator questions, will be analyzed to produce the following two methods-based analyses:

1) Assessment of data quality - This analysis will assess item-level non-response, presence of outliers, those with specific and repeated response patterns, and those suspected of not answering truthfully or false respondents.

2) Recruitment performance review – This analysis will assess the performance of ads that were used for recruitment, and include overall response rates to each of the surveys.

Those routed to the general population survey will answer questions related to use of breast cancer screening tests, information seeking behavior, and beliefs and perceptions associated with risk factors for breast cancer, as well as basic demographic information. Responses to this survey will be used in analysis for the following:

1) Explore mammography use among women aged 40 and over and barriers experienced in trying to obtain cancer screening
2) Describing awareness of risk factors for breast cancer among women 40 and over
3) Description of information seeking behavior and its impact on utilization of mammography.

Those who have previously been diagnosed with cancer of any kind will be routed to a survey designed specifically for cancer survivors. This survey will pose questions related to mental and physical health, satisfaction with cancer-related care, and the effects of cancer on employment and financial well-being.Analyses of interest include:

1) Describing quality of life and identifying common characteristics among those reporting challenges
2) Understanding use and access to mental health services among cancer survivors
3) Describing the effects of cancer on employment and financial health.

Individuals with a family history of cancer and/or who have had genetic testing/counseling will be routed to the high-risk survey. Questions will touch upon the experiences of sharing genetic information, the barriers to communicating genetic risk within families, and the outcomes of that communication. Specifically, we will address the following key research questions in the high-risk survey:

1) Facilitators and barriers to sharing genetic testing results with family members (family communication style, lack of information or resources, education level, having enough information to speak about familial cancer, number of family members with cancer).
2) Mechanism for sharing genetic test results with family members (by letter, by phone, in person, etc.), and for family members sharing results with respondent.
3) Sources of cancer information (internet, healthcare provider, etc. and resources provided to help inform your family about genetic risk (video, pamphlet, letter), including helpfulness of these resources and gaps in information.

Follow-up survey

We will then conduct a follow-up of these high-risk individuals as formative research exploring the experiences involved in communicating cancer risk in greater detail. Results from the follow-up survey will inform the development and testing of a decision aid that will facilitate decision-making about disclosure of genetic information within families. The follow-up survey will also allow us to understand if response rates from web-based follow-up surveys are comparable to those seen in more traditional survey research. All surveys will also include questions on participant socio-demographic characteristics.

Respondents to the follow-up survey will be recruited via email invitations to eligible respondents to the high-risk survey. Prior respondents will be sent a personalized email inviting them to participate in the survey, with a unique link to the web survey (**Attachment 7)**. Additional respondents may be recruited via advertisements placed on social media and search engine sites such as Facebook, Twitter, and Google, following the same procedure as described above for the original survey. Individuals meeting the age criteria, and who visit one of the websites will be eligible to view the recruitment ads **(Attachment 4).** Ads that were productive in recruiting eligible respondents for the high-risk survey will be used again in recruiting the follow-up sample. 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 **(Attachments 5a & 5c)**. To determine eligibility of interested respondents, the web survey includes a brief screener to assess eligibility as well as determine skip patterns for the questionnaire (**Attachment 6b**). For example, only those who report being female in the screener will be asked about BRCA1/2 testing.

 The following questions will be addressed in the follow-up survey:

1) What factors influenced your decision to get genetic testing (recommendation, knowledge of benefits, family support, etc.)
2) How satisfied were you with the communication about genetic testing you had with your healthcare provider?
3) How were you informed of the results of your genetic testing? What were those results?
4) How could the process for receiving your genetic test results have been improved?

Our goals are to advance research, inform public health efforts, and to develop tools for better communication of genetic cancer risk. With rapid growth in genetic and molecular medicine, information on susceptibility to a host of diseases is likely to be available to individuals who must then decide on whether to share and how to share genetic cancer risk information with family members. We need to better understand the barriers to communication as well as the information needs of persons found to be at

high risk for cancer to effectively incorporate genetic knowledge into medicine and into discussions with families. This insight will guide the development of tools and/or strategies that make genetics practically useful for individuals making decisions that could affect their own health or the health of family members. Study results will be disseminated through presentations for health professionals and publications in peer-reviewed scientific journals.

A.3.   Use of Improved Information Technology and Burden Reduction

This study will use the internet and social media platforms for subject recruitment. We expect that this method will provide benefits to simplifying data collection methods. We will use technological information where possible to reduce respondent burden.

(1) Voxco is a computer-aided interviewing (CAI) system that has functionality to administer the web survey with minimal user errors such as missing data or incorrect skip patterns. Use of a web survey will also reduce the time needed to complete the questionnaire. Transfer of data collected electronically will eliminate the need for data entry.
The Voxco system produces fully responsive, 508-compliant web pages capable of being comfortably viewed on a PC or Mac, tablet, or smartphone. It can be viewed through most modern browsers (including Internet Explorer, Chrome, Firefox, and Safari). Each questionnaire is programmed to create visual consistency with previously tested questions, examine potential user proficiency and technology limitations, and accommodate multiple technology platforms. Questionnaires are formatted to maximize readability, including appropriate question spacing, pixelation, font type and size, and properly programmed branching patterns. After the questionnaires were programmed, each questionnaire has undergone rigorous testing. Screenshots of the formatted questionnaires can be found in **Attachment 8a-e**.
(2) All websites used will generate automated paradata reports that will allow project staff to monitor the effectiveness of the recruitment method and the composition of the recruited sample. Combined with data from the CAI system, project staff will be able to report on recruitment results and make adjustments to the recruitment effort as needed.

In addition, in order to ensure data quality, technological advances will be used to help provide higher quality data. These methods include:
- **Global Nonresponse:** We programmed the survey so that respondents answering the first five questions after the screener as Don't know or Prefer not to answer will be redirected to the ineligibility screen. The first five questions selected are non-trivial and do not ask for sensitive information; therefore, we would expect respondents to know the answers.
  - o   This does not prevent respondents from answering a large number of questions in this fashion throughout the remainder of the survey (after the first five questions). Therefore,

at the end of data collection, we will review the total number of questions each respondent answered as Don't know or Prefer not to answer to identify a natural cutoff for case eligibility. For example, if the respondent answers 50% or more of the questions as Don't know or Prefer not to answer, they could be re-categorized as partial instead of complete.

- **RelevantID:** RelevantID is a digital fingerprint software that gathers a large number of data points from a respondent's device (computer, phone, tablet) such as operating system version, browser version, plug-in, etc. Upon first completing the survey, a respondent should receive a score close to zero. If the respondent tries to complete the survey again on the same device, they should get a score close to 100. We will be using a conservative cutoff score of 75, considering respondents with a higher score as likely duplicates and sending them to the ineligibility screen. Prior research has shown that, when used correctly, this system is effective at identifying potential duplicate users.

- **Google reCAPTCHA**: reCAPTCHA is a free service supported by Google that keeps automated software from engaging in data falsification. It asks the user to select a box, or in more complex scenarios (based on their proprietary risk analysis engine) to select all pictures containing crosswalks, for example, to prove that they are not a robot. This reCAPTCHA is required at the onset of the survey and also before a respondent receives their incentive. The user will be given a small number of opportunities to pass the reCAPTCHA before being kicked out of the survey.

- **Data Review**: NORC will conduct period data quality review to evaluate, among other things, users who report inconsistent or straight-line responses. These respondents will be coded with an 'Invalid' disposition in the final dataset and their data excluded from analysis.

- **Email Check**: Respondents are asked to provide an email address to receive a personalized link to the survey in the event of breakoff and to receive their incentive at the end. This is not required, so we view this as an accessory check but not a primary barrier to false entry. These email addresses are checked against the existing database before the respondent is allowed to continue. If they provide an email address already in our system, they are shown their incentive from the first completion and their record is marked as a duplicate and excluded from analysis. We also review the email addresses provided periodically and at the end of data collection and exclude cases that use clearly false email addresses like forgiftcodes@yahoo.com.

- **Daily Cap**: We set a daily cap for the number of respondents who can complete the survey on a given day. If we are identified by fraudulent users, the maximum number of data entries they can hit on a single day is limited. This allows us a greater chance of identifying the problem before incentives are depleted.

- **Phased Approach**: We will employ a phased approach to data collection with the survey. At points throughout data collection, ads will be turned off, and the survey temporarily closed while data quality is assessed. We will take this time to evaluate whether specific ads or platforms are especially useful or problematic and ad spend should be redirected. We will also recalibrate complete totals based on any cases that we determine are not of high enough quality to be included in analysis. Finally, if other problems are identified that can be resolved with programming solutions, the survey programmer or other IT staff will implement changes and re-testing will occur before the survey is re-fielded.

A.4. Efforts to Identify Duplication and Use of Similar Information

The Agency believes no other survey data collection effort has been conducted or has been planned to collect similar information for these populations. CDC conducted a review of similar studies prior to the issuance of the contract, and determined that this study is collecting unique information. The review of similar studies included: 1) attending public health and behavioral science conferences and meetings, such as the American Public Health Association Annual Meeting, and the Society of Behavioral Medicine annual meeting, to survey the latest research being conducted in cancer prevention and control, 2) conducting an informal literature review of survey-based research in cancer prevention and control to determine commonly used methodologies, 3) review of recently issued grants, cooperative agreements, and contracts by CDC and NIH for overlapping content, and 4) conversations with other researchers and experts who conduct survey based research. Research to date has not evaluated the usefulness of social media to recruit cancer-based study populations. While research studies, both within and outside of cancer prevention and control, might be using social media websites for online recruitment, we have not identified any studies who seek to assess feasibility, understand bias, identify best practices, and assess statistical methods for weighting or adjustment to answer questions of research method efficacy and effectiveness. Detailed information on family communication patterns has not been collected among high-risk individuals, nor has respondent perspectives on available tools and resources for communication of family genetic cancer risk been collected with a population of this size. Therefore, this research project requires the collection of this new primary data.

A.5.   Impact on Small Business or Other Small Entities

This data collection effort does not involve any small businesses or other small entities.

A.6. Consequences of Collecting the Information Less Frequently

In this data collection effort, a baseline web survey will be conducted with approximately 500 to 1,000 eligible individuals of each survey respondent type (general population, cancer survivors, individuals at high risk for cancer) to collect information on health care access, cancer screening, health status and outcomes, and utilization of genetic services. A follow-up web survey will be conducted with participants of the high risk survey who indicate they have had genetic testing; additional respondents who have had genetic testing may be recruited for the follow-up survey if the response rate is lower than expected.

This is a one-time, cross-sectional study with one or two data collection points, depending on the population. While there are no legal obstacles to reducing the burden further, collecting this information

less frequently would detract from the purpose of the study. Reducing the respondent burden below the estimated levels (i.e., reducing the number of participants) would reduce the power of the study to detect outcome measure differences (e.g., impact of cancer diagnosis on financial well-being; genetic testing patterns; and source of cancer information). In addition, eliminating the follow-up survey for high-risk individuals would limit our ability to obtain respondents' perspectives on unmet needs for communicating family genetic cancer risk and understand if response rates to web surveys vary from traditional mode follow-up surveys. This information is necessary for developing tools and resources for individuals receiving genetic testing for cancer risk. Keeping the follow-up survey separate from the original high-risk survey will keep the length of each survey at an acceptable length for web surveys while minimizing item-level non-response that can increase with survey length. Only key questions and topics are included in the surveys in order to respect respondent burden, by keeping the surveys as short in terms of administration time as possible.

A.7. Special Circumstances Relating to the Guidelines of 5 CFR 1320.5

There are no special circumstances with this information collection package. This request fully complies with the regulation 5 CFR 1320.5.

A.8.   Comments in Response to the Federal Register Notice and Efforts to Consult Outside the Agency

A. Federal Register Notice

In accordance with 5 CFR 1320.8(d), 09/18/2018, a 60-day notice for public comment was published in the *Federal Register* (**Attachment 10a**). Five comments were received. All five comments were positive and supportive of the goals and approach of the study. Specifically, the project was commended for developing innovative approaches to further cancer prevention and control efforts. The five comments received can be found in **Attachment 10b**, and a response to each individual comment can be found in **Attachment 10c**.

B. Efforts to Consult Outside the Agency

The study protocol, data collection plan, data collection instruments, and analysis plan have been discussed with individuals inside and outside the study team. A review of studies published in academic journals that utilized social media advertising for recruitment was conducted in 2016 to assess the state of the science on these methods and determine the extent of implementation of these methods in cancer prevention and control research. While this review identified that using

social media for research recruitment was not rare, it has been sparsely used in cancer prevention and control research. In addition, the project officer attended several professional conferences, including the American Public Health Association and the Society of Behavioral Medicine annual meetings, to seek out presentations on research utilizing these methods and speak to researchers utilizing these research methods. Few researchers were utilizing these methods for fear of potential sampling bias and lack of familiarity with methods for weighting the sample or adjusting estimates to address bias. The project has also benefited from input from individuals with varying expertise. Specifically, the project consulted with Dr. Lila Rutten at the Mayo Clinic for this project. Her contact information is listed below.

Lila Rutten, PhD
Professor of Health Services Research
Mayo Clinic Cancer Center
200 First Street SW
Rochester, MN 55095
Rutten.lila@mayo.edu
507-293-2341

A.9.   Explanation of Any Payment or Gift to Respondents

We will provide all respondents who complete the web survey with a token of appreciation totaling $5 to encourage their participation, and convey appreciation for contributing to this important study. Numerous studies have shown that tokens of appreciation can significantly increase response rates and the use of modest tokens of appreciation is expected to enhance survey response rates without biasing responses (Abreru & Winters, 1999; Shettle & Mooney, 1999; Göritz, 2006).

In his memorandum for the President's management council dated January 20, 2006, the Administrator of the Office of Information and Regulatory Affairs of the Office of Management and Budget wrote, "Incentives are most appropriately used in Federal statistical surveys with hard-to-find populations or respondents whose failure to participate would jeopardize the quality of the survey data (e.g., in panel surveys experiencing high attrition), or in studies that impose exceptional burden on respondents, such as those asking highly sensitive questions…" Offering tokens of appreciation is considered necessary to recruit minorities and historically underrepresented groups in to research studies. This project aims to recruit a diverse sample in terms of race/ethnicity while also targeting hard-to-reach populations (cancer survivors and those who have received genetic testing); given these goals, this study will especially benefit from tokens of appreciation. In addition, the questionnaires ask about sensitive topics that justify the use of incentives. Topics such as family history of cancer, personal history of cancer, genetic testing, and utilization of medical services are generally found to be sensitive in nature for respondents.

Only those who complete the survey will receive the $5 gift card incentive. Respondents completing the survey will receive the token of appreciation regardless of whether they skip any questions.

A.10. Protection of the Privacy and Confidentiality of Information Provided by Respondents

We will inform all respondents that their responses will be kept private to the extent permitted by the law. All respondents surveyed will be informed that the information collected will not be attributable directly to the respondent, will only be analyzed in aggregate, and will only be shared with members of the study team. Terms of the CDC contract authorizing data collection require the contractor to maintain the privacy of all information collected. Because respondents will be asked potentially sensitive information in the form of a detailed family history of cancer, whether they have undergone BRCA1/BRCA2 genetic testing, and the results of those genetic tests, CDC is seeking a 301(d) Certificate of Confidentiality of the Public Health Service Act for this study. This certificate is important to protect sensitive individual information and provides additional assurance that all answers given by participants will be kept private and that no information will be shared with anyone outside the study staff, even under court order. Persons may not be willing to share this sensitive information without such an assurance of privacy.

Since the passing of the 21st Century Cures Act amended section 301 of the Public Health Service Act, all CDC supported research started or ongoing after December 31, 2016, an in which identifiable, sensitive information is collected, is protected by a certificate. Therefore, this study is protected by a Certificate of Confidentiality (COC). Due to this change, individual COC certificates are no longer issued for studies. This is reflected in the Informed Consent language (**Attachments 5a-5c**).

The data files delivered to CDC will exclude personal identifiers. The survey data will be analyzed in aggregate, and no individual respondents will be identified. In both the baseline surveys and the follow-up survey, respondents will be assured that what they say will be kept private. Their answers will not be linked to their name or to other personal information in any report or publication. Only study staff at the contractor will have access to identifying information. Data from the eligibility screener portion of the questionnaire will be counted as a category of potential responses to the invitation to participate in this survey.

Key safeguards have been put in place to assure respondents that their responses will be treated in a secure and private manner. Prior to any screener questions, the prospective respondent will be shown a landing page with informed consent text **(Attachments 5a & 5c)**. The informed consent language is written in simple language (grade 7.5 Flesch-Kinkaid reading level). In addition to the landing page, a

Frequently Asked Questions (FAQs) link will be provided at the bottom of each survey page (**Attachment 5b**). Consent includes a brief description of the study and contains the following key points:

- Purpose of the study
- Study procedures
- Question topics
- Estimated time required to participate
- Disclosure of incentive
- Potential risks and benefits
- Statement that participation is voluntary
- Telephone numbers of persons they may contact with further questions
- Authority for the data collection

Some PII will be collected temporarily as part of this study. We plan to collect participant name, e-mail address, IP address, and mailing address, including state/city/zip code. Participant name and email address are being collected in order to send an email to each respondent with a link to the study survey if they want to complete it in more than one sitting, and, when appropriate, invite them to participate in a follow-up survey. Mailing address will be used to send them their survey incentive ($5 gift card). IP address is solely being collected to identify duplicate survey administrations from the same computer. All PII will only reside at the contractor site (NORC) and will never be delivered to shared with CDC. Participant e-mail addresses, and IP addresses will be deleted by the contractor at the end of the data collection period. Respondent names and mailing addresses will be deleted once all survey incentives have been mailed. Respondent zip code will be used to create statistical weights and will be deleted once the weight variable is finalized. All PII collected will be deleted by the contractor and never sent to CDC. Only de-identified data sets will be delivered to CDC. The contractor will house PII in a separate database as the survey responses and only certain staff know will have access to the PII data. NORC (CDC's contractor) implements access on the least privilege method. Only people whose jobs require access to the data are granted the appropriate level of access. Staff with access to PII was limited to only study team members and the data files with PII are being saved in secure locations. Only the sampling statistician who is designing survey weights will have access to geographical information. They will not have the ability to link the PII with survey responses to protect identities. IP addresses will only be accessible by those who are ensuring fraudulent data entry. Name, address, and e-mail address will only be accessible by staff who are mailing incentives or sending out reminders about survey participation. A signed Privacy Impact Assessment Form is included in **Appendix 11**.

A.11.   Institutional Review Board (IRB) and Justification for Sensitive Questions

IRB Approval

This study was approved by NORC's IRB in 2017. The most recent approval letter can be found in **Attachment 9a**. The CDC IRB in the Human Research Protections office approved a request to allow reliance on the NORC IRB approval (**Attachments 9b and 9c**). We sought for CDC IRB to reliance on the NORC IRB decision because this data collection effort poses minimal risk to the respondent.

Sensitive Questions

The proposed data collection includes sensitive information related to the respondent's personal and family history of cancer, and their utilization of medical tests and cancer screening services. In addition, questions concerning education level or income may be viewed as sensitive by a portion of respondents. We will also be asking participants about their race and ethnicity. Although our sample size will not permit stratification by race/ethnicity for all outcomes of interest, we expect to be able to examine cancer screening practices (general population survey), general health and well-being (cancer survivor survey), and communication patterns with family members (high risk survey) stratified by race/ethnicity. There may be important differences in psychological constructs such as cancer worry and confidence in testing by race/ethnicity that we will want to carefully examine (Consedine et al., 2004). Furthermore, race, as well as income and medical care access, will be important control variables in multivariate analyses. The sensitivity of the data to be collected necessitates privacy protection.

Additionally, some participants may feel uneasy or uncomfortable answering some of the questions about their experiences with cancer and their thoughts about genetic testing results. Sensitive information is required in order to describe and understand the relationship between testing experience and family communication about testing results, and we will ask respondents to provide a detailed history of cancer and genetic testing in their family as part of their testing experience summary. A strong family history of cancer may be indicative of a genetic mutation such as BRCA1/BRCA2. We will also ask if individuals have undergone genetic testing and the results of that test. Both family history of cancer and genetic testing could be considered sensitive information. Knowing if a person has a strong family history of cancer is imperative for proper classification into the high-risk survey or general population survey.

To minimize psychological distress, participants will be informed that they may skip over any questions that they do not want to answer and that they may stop participating at any time. As described above, the project is concurrently pursuing a Certificate of Confidentiality to further safeguard participant privacy as it relates to sensitive personal information such as questions about genetic testing. Participants will be

given the toll-free telephone numbers of the project COR at CDC as well as the NORC IRB to answer questions pertaining to the study or their rights as a research volunteer. We will direct all individuals who complete the survey to the following resource page:

https://www.cdc.gov/cancer/dcpc/resources/index.htm.

A.12.   Estimates of Annualized Burden Hours and Costs

Burden

The estimate of burden for the instruments is based on cognitive interviews with nine respondents. A variety of instruments and platforms will be used to collect information from respondents. The annual burden hours requested (1,646) are based on the number of collections we expect to conduct over the requested period for this clearance.

The estimated burden per response for the screener is 2 minutes (**Attachment 6a-6b**). We anticipate that we will need to screen 1,500 individuals to meet our target (n=500) of women over 40, 3,000 individuals to meet our target (n=750) for the survivorship survey, 2,000 individuals to meet our target (n=750) for the high-risk survey, and 4,000 individuals to meet our target (n=750) for the follow-up survey. This is a total of 10,500 individuals, or a total of 350 burden hours.

The estimated burden per response for the women over 40 survey (**Attachment 3a**) is 28 minutes per individual, or 233.3 burden hours. The estimated burden per response for the cancer survivorship survey (**Attachment 3b**) is 30 minutes per individual, or 375 burden hours. The estimated burden per response for the high-risk survey (**Attachment 3c**) is 30 minutes per individual, or 375 burden hours. The estimated burden per response for the follow-up survey (**Attachment 3d**) is 25 minutes per individual, or 312.5 burden hours. While the High Risk follow-up survey may seem longer than the time estimated, that is because some questions from the high-risk survey will are included but will only be fielded if left blank or incomplete. The burden for these questions is included in the High-Risk Survey burden. Total burden hours for the survey data collection is estimated to be 1,645.83, or 1,646 hours.

Respondent Cost

Table A12-2 presents the calculations for cost of burden hours. Average hourly wages were used to calculate the cost of burden for adults to participate. Hourly wage information is from the U.S. Department of Labor, Bureau of Labor Statistics web site (http://www.bls.gov/home.htm) as of May 2015. The total estimated annualized respondent cost is $38,232.71 This cost represents the total burden hours to respondents multiplied by the average hourly wage rate for adults ($23.23).

Table A12-1

	Estimated Total Reporting Burden Hours			
Type of Collection	No. of Respondents	Annual Frequency per Response	Hours per Response	Total Hours
Women over 40 - Survey Screener	1500	1	2/60	50
Cancer Survivors - Survey Screener	3000	1	2/60	100
Adults at High Risk for Cancer - Survey Screener	2000	1	2/60	66.7
Adults at High Risk for Cancer - Follow-Up Screener	4000	1	2/60	133.3
Women over 40 - Breast Cancer Survey	500	1	28/60	233.3
Cancer Survivors - Survivorship Survey	750	1	30/60	375
Adults at High Risk for Cancer - High-Risk Survey	750	1	30/60	375
Adults at High Risk for Cancer - High-Risk Follow-Up Survey	750	1	25/60	312.5
Total				1,646

Table A12-2

Type of Collection	No. of Respondents	Total Burden Hours	Hourly Wage Rate	Total Costs
Women over 40 - Survey Screener	1500	50	$23.23	$1,161.50
Cancer Survivors - Survey Screener	3000	100	$23.23	$2,323.00
Adults at High Risk for Cancer - Survey Screener	2000	66.7	$23.23	$1,548.67
Adults at High Risk for Cancer - Follow-Up Screener	4000	133.3	$23.23	$3,097.33
Women over 40 - General Population Survey	500	233.3	$23.23	$5,420.33
Cancer Survivors - Survivorship Survey	750	375	$23.23	$8,711.25
Adults at High Risk for Cancer - High-Risk Survey	750	375	$23.23	$8,711.25
Adults at High Risk for Cancer - High-Risk Follow-Up Survey	750	312.5	$23.23	$7,259.38
Total				$38,232.71

A.13. Estimates of Other Total Annual Cost Burden to Respondents or Record Keepers.

There will be no direct costs to the respondents other than their time to complete the survey.

A.14. Annualized Cost to the Government

The anticipated cost to the Federal Government is approximately $563,013 annually. These costs are comprised of two types of government costs: (1) government personnel, and (2) contracted data collection.

1. The COR is assigned for 25% of his time, and a CDC epidemiologist is assigned for 10% of her time. Assuming an annual salary of $106,879 for the COR, and $138,296 for the epidemiologist, a total paid to government personnel annually is $40,550.

2. The data collection is being conducted under a contract with NORC at the University of Chicago. This contract has a value of $522,463.

There are no equipment or overhead costs. The only cost to the federal government will be the salary of CDC staff and funding for the contractor, NORC, to support the development of the study design, data collection, and associated tasks.

Exhibit A14.1: Annualized Cost to the Government

Expense Type	Expense Explanation	Annual Costs (dollars)
Direct Costs to the Federal Government	CDC, COR (GS-13, 0.25 FTE)	$26,720.00
	CDC, Epidemiologist (GS-14, 0.1 FTE)	$13,830.00
	Subtotal, Direct Costs	$40,550.00
Cooperative Agreement or Contract Costs	Contract Cost: NORC @ University of Chicago	$522,463.00
	Subtotal, Contract Costs	$522,463.00
	TOTAL COST TO THE GOVERNMENT	**$563,013.00**

A.15 Explanation for Program Changes or Adjustments

This is a new information collection request (ICR).

A.16. Plans for Tabulation and Publication and Project Timeline
16.1 Time Schedule

Data collection is scheduled to begin in November 2019 and continue for approximately 6 months. The high-risk follow-up survey will be conducted immediately following the initial wave of data collection with those respondents who completed the initial survey and/or newly recruited high-risk women and will continue in the field during months 2-6 of data collection. Table A16-1 presents the estimated timeline for this study. A one (1)-year clearance is requested.

Table A16-1: Project Time Schedule

Study Activity	Estimated Date of Completion
Study logistics	Concurrent with OMB review
Baseline Surveys	
Recruitment & data collection	1-6 months after OMB approval
Analysis, interpretation, and reporting	7-12 months after OMB approval
Follow-Up Survey	
Recruitment & data collection	2-6 months after OMB approval
Analysis, interpretation, and reporting	7-12 months after OMB approval

16.2 Publication Plan

Results of the study will be disseminated through presentations at scientific meetings and publications in peer-reviewed journals. We will initially focus on the hypotheses outlined for this study (in Section A2) and anticipate the development of manuscripts on the following methods-based topics:

1. What is the quality of the data collected across the three surveys?
2. What ads were most effective in recruitment? What were survey response rates?

Women over 40:

1. How many women reported being regularly screened for breast cancer with mammogrpahy?
2. What do women believe causes breast cancer and can influence their risk?
3. How do respondents seek information on cancer, health, and cancer screening? Does information-seeking behavior have an impact on utilization of mammography?

Survivorship:

1. What factors are associated with quality of life and well-being after cancer?
2. How do cancer survivors utilize and access mental health services?
3. How does cancer affect employment and financial health?

High-risk (including data from both high risk and high risk follow-up surveys):

1. What are the facilitators and barriers to sharing genetic testing results with relatives?
2. From which sources do respondents get cancer information and what sources have been helpful in family discussions? What are the information needs of high-risk persons?
3. What factors influenced the respondents' willingness to undergo genetic testing?
4. What are the motivations for disclosure or non-disclosure of genetic information with relatives?

All abstracts, poster presentations, and manuscripts will undergo CDC clearance review prior to submission to conferences or journals.

Consistent with the Supporting Statements, the methods for recruiting participants for this study limit CDC's ability to make inferences about broader populations, and as such, OMB approves this collection consistent with the understanding that CDC will only be conducting formative research that will not be used as influential information to support agency policies or decisions. Approval for collection through social media sampling is provided specifically for the purposes of capturing diverse experiences from a hard to reach population and informing more robust future studies. When communicating findings from this collection, all publications will clearly describe the scope and limitations of the methods and findings. Approval is provided contingent upon a commitment to work with the National Center for Health Statistics to ensure there is no duplication of efforts; should modifications to the methodology, data quality, or instruments be necessary, CDC will consult with both NCHS and OMB in advance of submission. CDC commits to peer review on all publications based upon this research and will share final copies with OMB.

16.3 Tabulation Plan

CDC and NORC will prepare the draft analyses, tables, and figures for scientific articles and study report(s) that address the formative research questions. Results will present descriptive statistics and logistic regressions to understand the research questions presented above, based on variables collected in the surveys.

Data Quality Analyses

We will begin with analyses relative to the uniqueness of the methodological approach used in these studies. There are two methodological research questions. We plan to conduct analyses that include descriptive statistical techniques to address the following questions:

1.   What is the quality of the data collected across the three surveys?

Descriptive analyses will be conducted to report the quality of the data obtained from each of our study surveys. This analysis will describe the amount of item-level non-response, the presence of outliers and those with specific and repeated response patterns, and those suspected of not answering truthfully or providing false reports. This will be done by assessing the number of biologically non-plausible or extremely rare cancers (e.g. a woman with prostate cancer at age 4), or those who report having genetic test, but not reporting have had a specific BRCA1/2 test. In addition, we will report attempts to fill out the survey multiple times from the same IP address, those with false or leading e-mail addresses, and the other methods detailed in section A.3, whenever possible. This report will describe the number of respondents that were excluded or dropped from the survey to ensure that analyses are only conducted on those respondents who have provided quality data.

2.   What ads were most effective in recruitment? What were survey response rates?

This analysis will provide detailed descriptions of the recruitment process and an evaluation of the methods used to recruit each sample. We will describe how the surveys were carried out, results by population using validated methods for web-based surveys, such as the Checklist for Reporting Results of Internet E-Surveys (CHERRIES), , and a descriptive analysis of the populations recruited (Eysenbach, 2004). Additionally, we will use published and federally accepted means for assessing response rates in Federal Health Surveys collecting data using social media (Crosier, Brian, & Ben-Zeev, 2016). Taken together, these strategies will provide as accurate a simulated response rate as possible for this non-probabilistic approach.

We will examine how each recruitment advertisement performed across the social media and search engines. In addition, we will evaluate the efficacy and cost of using Facebook, Twitter, or Google as a means of recruitment.

Women aged 40 and over analyses

1. How many women reported being regularly screened for breast cancer with mammogrpahy?The United States Preventive Services Task Force (USPSTF) has issued screening recommendations for regular breast cancer screening (U.S. Preventive Services Task Force, Final Recommendation, 2016; U.S. Preventive Services Task Force, Final Update, 2016; U.S. Preventive Services Task Force, 2017). Assessing factors associated with recommendation compliance can aid in the identification of those least likely to be screened appropriately and help develop targeted intervention efforts to increase screening rates. This analysis will focus on assessing demographic and medical factors that may impact utilization of mammography.

These analyses will consist of 2 binary outcomes: 1) being rarely or never screened for breast cancer; and 2) compliance with breast cancer screening recommendations.. In addition, we will explore repeated use of mammography screening over a 5-6 year period to attempt to better understand mammography rescreening. Descriptive analyses will be conducted to report the percentage of women who report having had a mammogram (or not had a mammogram), and those who report being re-screened. We will also report percentages describing patterns of re-screening. Bi-variate analyses, namely cross-tabulations, will be used to present mammography use by respondent demographic characteristics and reported levels of access to care. In addition, barriers to mammography use, such as transportation, and office hours, and exposure to interventions to increase mammography screening rates, will be calculated as percentages. Chi-Square tests or ANOVAs will be used to test for statistical significant in bi-variate analyses.

2. What do women believe causes breast cancer and can influence their risk?

Beliefs on the causes of cancer may provide guidance on priorities for breast cancer prevention communications efforts (Rodriguez V, 2014). These analyses will provide some initial information to CDC on future research on cancer risk factors and areas of knowledge and misinformation that can serve as targets for educational efforts. Descriptive analyses will be conducted to analyze survey questions associated with relative importance of cancer risk factors and beliefs associated with particular risk factors. Percentages will be used to describe cancer attributions. Summed scores will be created to describe overall knowledge about breast cancer risk factors. Bi-variate analyses will be conducted to

explore cancer attributions and knowledge of risk factors by socio-demographic characteristics. Chi-Square tests and ANOVA will be used to test for any statistically significant differences.

1. How do respondents seek information on cancer, health, and cancer screening? Does information-seeking behavior have an impact on utilization of cancer screening?

Having knowledge about cancer screening and understanding its benefits may have a significant impact on screening utilization (Schneyderman et al., 2016; Gibson, 2016; Wigfall & Friedman, 2016; Sinky, Faith, Lindly, & Thorburn, 2018). This analysis will explore cancer related information seeking behavior and its impact on uptake of mammography. Descriptive analyses will be conducted to explore sources of information on cancer and experiences in searching for information. In addition, a logistic regression model will be developed to assess demographic characteristics associated with cancer-related information seeking behavior. Next, we will explore the relationship between cancer-related beliefs and information seeking. Namely, we are interested in understanding the relationship between cancer risk perceptions, cancer-related worry, and beliefs about screening vary among those who have sought out cancer related information and those who have not. This will be done though bivariate analyses, specifically crosstabs and chi-square tests. Finally, we will assess the relationship between cancer information-seeking behavior and utilization of cancer screening tests through logistic regression. Correlates of interest will include cancer-related beliefs explored in the prior analysis, information seeking behavior, and demographic factors.

Cancer survivorship survey analyses

1. What are the factors associated with quality of life and well-being after cancer?

Mental and physical health, two of the main components of health related quality of life, are important outcomes to assess in cancer survivors. Due to the late and long-term effects associated with cancer treatment, understanding cancer survivors' quality of life can help us identify vulnerable groups and design targeted interventions to address physical or mental health issues (Institute of Medicine and National Research Council, 2006).The purpose of this exploratory analysis is to assess factors associated with mental and physical health among cancer survivors. Using the PROMIS global health scale (Cella et al., 2010) to develop scores for mental (MH) and physical health (PH), those who report scores 1 standard deviation below the population mean, will be considered to have poor quality of life. A logistic regression will be used to assess factors associated with poor quality of life. Regressions will be run for each MH and PH score below 1 standard deviation from the population mean. Predictors of interest will include

demographic characteristics like age, race/ethnicity, and marital status, and cancer-related characteristics like cancer type, time since diagnosis, and type of cancer treatment received.

2. How do cancer survivors utilize and access mental health services?

In addition to quality of life issues associated with mental health, cancer survivors are often encouraged to seek support services, like counseling or use of a support group, and are often prescribed psychotropic medication like anti-depressants or anti-anxiety medication (Institute of Medicine and National Research Council, 2006; Forsythe et al., 2013; Hawkins, Soman, Buchanan Lunsford, Leadbetter, & Rodriguez, 2016). The purpose of this analysis is to explore use of support services by cancer survivors and prevalence of psychotropic medication usage among cancer survivors. To assess utilization of support services, descriptive analyses will be conducted to assess types of support services used by survivors. A logistic regression model will be run to assess characteristics associated with seeking or utilizing support services. Predictors of interest will include sociodemographic characteristics and cancer-related characteristics, similar to those proposed in the quality of life analysis above.

In addition, two logistic regression models will be run to assess use of anti-depressants and anti-anxiety medication. The regression models will include sociodemographic and cancer related characteristics as key predictors of interest. In addition, descriptive analyses will be conducted to assess which providers are prescribing these medications and timing of prescriptions (pre/post cancer diagnosis).

3. How does cancer affect employment and financial health?

Financial distress and issues associated with employment have been previously described among cancer survivors (Duijts, et al., 2014; Yabroff et al., 2016). This analysis will explore employment related issues faced by cancer survivors and describe financial distress and toxicity that cancer survivors might face, as well as the role of health insurance in employment issues and financial distress. Descriptive analyses will be conducted to describe the pre-cancer employment status and any transitions in employment status post-cancer. In addition, the prevalence of other employment considerations, such as job lock and early retirement will also be explored. A logistic regression model will be run to assess factors associated with financial distress. Covariates of interest will include sociodemographic factors and cancer-related characteristics.

High-risk and high-risk follow-up surveys analyses
We first will use descriptive statistics to summarize the characteristics of the 2 study samples and examine the distribution of individual variables. For scales that were drawn from the literature and are

being used as they were originally designed, scale scores will be calculated as described by the instruments' developers. Means and standard deviations will be calculated for the scale items and where possible, compared to scores reported in the literature. Exploratory factor analysis may be used to examine subscales of importance. We will conduct a series of analyses employing descriptive statistics (means, medians, t-tests, and chi-square tests), linear and logistic regression, and other multivariate techniques to address the research questions outlined in Section A2—Purpose and Use of Information Collection. We will focus on 4 key research questions although several additional analyses could be conducted using data collected from these surveys.

1) What are the facilitators and barriers to sharing genetic testing results with relatives?

The first analysis will focus on the predictors of sharing genetic information with family members. We will use a socio-ecologic conceptual model to frame demographic and psychosocial characteristics at the individual, family, and healthcare provider levels that influence disclosure of genetic information to relatives. This outcome can be dichotomized or examined as a continuous variable. Predictors potentially will include age, education, number of relatives with cancer, family communication style, lack of information resources, satisfaction with healthcare provider communication about familial cancer, results of genetic testing, finding resources provided by genetic counselor to be helpful, and ease of speaking with relatives about family cancer.

We will use percentages and overall chi-square tests to describe the distribution of characteristics associated with disclosure of genetic information. To examine the predictive power of the independent variables on our outcome, we will conduct a multivariate logistic regression analysis with hierarchical entry in three steps: the block of individual level characteristics entered first, then family-level characteristics, and finally provider characteristics. Entering the three sets of independent variables sequentially will allow us to examine the unique contribution above and beyond each group of variables. We will compute odds ratios or adjusted percentages from logistic models.

For comparative purposes, we will also present selected variables and constructs stratified by type of genetic test (BRCA1/2 or Lynch syndrome) and conduct multivariate analyses separately by type of genetic test.

2) From which sources do respondents get cancer information and what sources have been helpful in family discussions? What are the information needs of high-risk persons?

Using percentages, we will describe the relative importance of cancer resources available to respondents. These variables include speaking with primary care providers about cancer family history, ever seeking

information on genetic cancer risk, where information was sought (internet, books, cancer organizations, family, physician, etc.), how difficult information was to find, how understandable the information was, and concern about quality of information. We will use cross tabulations and chi-square tests to examine the effort required to find information, quality of information, and the comprehensibility of information for each source of information the respondent lists.

A secondary analysis will use descriptive statistics (percentages and means) to examine types of information on cancer risk provided by physicians, nurses, and genetic counselors to help inform family members about cancer risk (letter, printed materials, laboratory test results, cancer organizations, etc.). We will further describe responses to questions about the helpfulness of resources, having enough information about genetics and cancer to speak with family, and suggestions for other information that would be useful for discussions about cancer family history (printed materials, physician discussions, genetic counselor discussions, referral to support group, etc.).

3) What factors influenced the respondent's willingness to undergo genetic testing?

We will focus on the key predictors of genetic testing that include: age, education, perceived risk of cancer, cancer worry, cancer family history, number of family members involved in discussions about genetic testing, decisional conflict scale (knowledge about options, knowledge about risks and benefits, having support, etc.), ease of family discussions about genetic testing, and relatives' genetic testing history. Descriptive statistics and bivariate relationships between predictors and genetic testing will be examined and we will use logistic regression modeling to calculate odds ratios and 95% confidence intervals for the relationship between predictors and genetic testing and the relative importance of the variables in predicting genetic testing.

4) What are the motivations for disclosure or non-disclosure of genetic information with relatives?

We will use percentages and means to describe variables related to motivations for disclosure of genetic information for those who shared information with family members. These include ease of speaking with relatives, number of relatives with whom information was shared, how information was shared (phone, email, text, in person), reason for sharing genetic test results (felt responsibility, request from family for information, advised by genetic counselor), effort required for sharing, concern with quality of information that was shared, time the respondent spent in talking about testing with relatives and thinking about their own experience with testing, genetic testing among other family members, and closeness with relatives with whom genetic test results were shared. For those respondents who did not disclose genetic information we will describe reasons for non-disclosure.

A.17. Reason(s) Display of OMB Expiration Date is Inappropriate

We are requesting no exemption.

A.18. Exceptions to Certification for Paperwork Reduction Act Submissions

No certification exemption is being sought. These activities comply with the requirements in 5 CFR 1320.9.

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