

**Social and Economic Barriers to Receiving Optimal Services Along the Cancer
Care Continuum**

[OMB No. if applicable. 0920-xxxx]
[OMB expiration date]

Supporting Statement B

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8/15/2024

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ATTACHMENTS

1. Public Health Service Act [42 U.S.C. 241]
- 2a. Wave 1 Survivor Survey_online_English
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- 4g. Caregiver Survey_recruitment communications

- 4h. Caregiver Survey_recruitment communications_Spanish
- 5a. Survivor Interview Guide
- 5b. Survivor Interview consent form
- 5c. Survivor Interview recruitment materials
- 6a. Caregiver Interview Guide
- 6b. Caregiver Interview consent form
- 6c. Caregiver Interview recruitment materials
- 7a. Patient and Survivor Advocacy Organization Focus Group Guide
- 7b. Patient and Survivor Advocacy Organization Focus Group consent form
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- 8. Cancer Registry Data Fields
- 9. Federal Register Notice
- 10. Human subjects document
- 11. All Participant Types_One-page recruitment flyer

B. COLLECTIONS OF INFORMATION EMPLOYING STATISTICAL METHODS

B1. Respondent Universe and Sampling Methods

This information will be collected from individuals previously diagnosed with female breast, cervical, or colorectal cancer in 2021, who were 21-75 years old at the time of their diagnosis, are Black American, White, or Hispanic, and lived in California, North Carolina or Texas at the time of their diagnosis. We will ask state cancer registries to provide us with a sampling frame that meets our eligibility criteria.

The contractor will administer a Wave 1 Survivor Survey, Wave 2 Survivor Survey, and a Caregiver Survey to individuals identified above. The Wave 1 Survivor Survey will be available in English and in Spanish as a web-based survey (**Attachment 2a** and **Attachment 2c**) and as a paper survey (**Attachment 2b** and **Attachment 2d**). We will invite approximately 12,000 individuals to complete the Wave 1 Survivor Survey. Based on past studies, we anticipate that the Wave 1 Survivor Survey will be completed by up to 3,000 respondents and a subset of these respondents (n=1,200) will complete the Wave 2 Survivor Survey in English or Spanish as a web-based survey (**Attachment 3a** and **Attachment 3c**) or as a paper survey (**Attachment 3b** and **Attachment 3d**). Each respondent who completes the Wave 1 Survivor Survey will be asked to provide the contact information for one of their caregivers to complete the Caregiver Survey. The Caregiver Survey is designed to take no more than 15 minutes to complete. The Caregiver Survey will be available in English and in Spanish as a web-based survey (**Attachment 4a** and **Attachment 4c**) and as a paper survey (**Attachment 4b** and **Attachment 4d**). Only individuals who complete the Wave 1 survey and provide contact information will be invited to complete the Wave 2 survey and asked to provide contact information for their caregivers, which will be at most 12,000 participants for both the Wave 2 survivor and caregiver surveys. However, as indicated above, based on previous studies we only expect 3,000 individuals to participate in the Wave 2 survey and we expect 900 caregivers to complete the caregiver survey.

Participants from the Wave 1 and Caregiver Surveys will have the option to volunteer to be contacted for a one-hour interview at the end of their surveys. We will reach out to approximately 25 volunteers from each survey with the goal of interviewing 20 individuals who were previously diagnosed with cancer and 20 caregivers. We will hold focus groups with staff from patient/survivor advocacy organizations; there will be 2 focus groups, with 8 respondents in each group.

Respondent Type	No. in Respondent Universe	Sampling Frame	Desired No. in Final Sample	Expected Response Rate	No. to be Sampled
(1) Individuals who were previously diagnosed with cancer					

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Respondent Type	No. in Respondent Universe	Sampling Frame	Desired No. in Final Sample	Expected Response Rate	No. to be Sampled
Wave 1 Survey participants	71,666*	12,000	3,000	30%	12,000
Wave 2 Survey participants	12,000	3,000	1,200	40%	3,000
Interviewees	1,200	25	20	80%	20
(2) Caregivers					
Caregiver Survey participants	12,000	12,000	900	30%	3,000
Interviewees	900	25	20	80%	20
(3) Representatives from Advocacy Organizations					
Focus group participants	150**	20	16	80%	16

*Source: Cancer Registry of Greater California (crgc-cancer.org) and United States Cancer Statistics (<https://www.cdc.gov/cancer/uscs/index.htm>)

**We estimate that there are about 50 cancer advocacy organization representatives per state, and we are working with three states in our study.

B2. Procedures for the Collection of Information

Once IRB and OMB approvals are received, we will initiate a series of recruitment-related communications (**Attachment 2g** for English, **Attachment 2h** for Spanish), beginning with an invitation to complete the Wave 1 Survivor Survey via web, to eligible individuals who were previously diagnosed with cancer; these individuals will be identified through the state cancer registries. The web-based Wave 1 survey instrument (**Attachment 2a** for English, **Attachment 2c** for Spanish) contains 91 questions in English and Spanish and includes a mix of open and close-ended questions as well as optional open text boxes. The survey will display the appropriate questions depending on the participant's answers to previous questions. Participants may access the survey by directly typing the link on this letter or by scanning a QR code with their smart phone or tablet and then entering the custom access code (a unique participant ID# randomly assigned by the contractor) on the letter. This mailing will include a hard copy consent form (**Attachment 2e** for English, **Attachment 2f** for Spanish); participants may indicate passive consent online before beginning the survey by clicking past the consent language to begin the survey.

Two weeks after the first mailing, we will send a reminder postcard (**Attachment 2g** for English, **Attachment 2h** for Spanish) containing the same survey link, QR code, and **Social and Economic Barriers to Receiving Optimal Services Along the Cancer Care Continuum**

personalized access code. The postcard will be folded and sealed. Non-respondents will receive another, follow-up letter two weeks later (**Attachment 2g** for English, **Attachment 2h** for Spanish) with a survey link and QR code, followed by a mailing in another two weeks (**Attachment 2g** for English, **Attachment 2h** for Spanish) with the printed survey (**Attachment 2b** for English, **Attachment 2d** for Spanish) to complete and mail back. The mailing with the printed survey (which contains 91 questions) will also include a prepaid business reply envelope, to minimize burden of returning the completed survey. The paper survey responses will be electronically scanned and saved to the contractor's secure project folder. Our final outreach attempt will be a phone call two weeks after the paper survey is mailed (script is located in **Attachment 2g** for English, **Attachment 2h** for Spanish) to confirm participants have received the survey invitation and offer to answer any questions they may have. Participants who do not complete the survey within two weeks after the phone call will be considered "final refusals," and no further follow-up attempts will be made.

Survivors who complete the Wave 1 survey will receive a series of recruitment-related communications (**Attachment 3g** for English, **Attachment 3h** for Spanish), beginning with an invitation (**Attachment 3g** for English, **Attachment 3h** for Spanish) to complete the web-based Wave 2 Survivor Survey (**Attachment 3a** for English, **Attachment 3c** for Spanish) approximately one year later; this mailing will include a consent form (**Attachment 3e** for English, **Attachment 3f** for Spanish). The web-based Wave 2 Survivor Survey instrument contains 60 questions in English and Spanish and includes a mix of open and close-ended questions as well as optional open text boxes. The survey will display the appropriate questions depending on the participant's answers to previous questions. Participants will receive the same series of follow-up communications as Wave 1, each two weeks apart: reminder postcard (**Attachment 3g** for English, **Attachment 3h** for Spanish); follow-up mailing (**Attachment 3g** for English, **Attachment 3h** for Spanish); paper survey mailing (**Attachment 3g** for English, **Attachment 3h** for Spanish); phone reminder (**Attachment 3g** for English, **Attachment 3h** for Spanish). The paper survey (**Attachment 3b** for English, **Attachment 3d** for Spanish) contains 60 questions in English and in Spanish. The paper survey responses will be electronically scanned and saved to the contractor's secure project folder.

Individuals who were previously diagnosed with cancer and who completed the Wave 1 survey will also be asked to provide contact information for an adult caregiver (age 21 years or older) who may be interested in taking the Caregiver Survey. The web-based Caregiver survey instrument (**Attachment 4a** for English, **Attachment 4c** for Spanish) contains 63 questions in English and in Spanish and includes a mix of open and close-ended questions as well as optional open text boxes. The survey will display the appropriate questions depending on the participant's answers to previous questions. We will send a series of recruitment-related communications (**Attachment 4g** for English, **Attachment 4h** for Spanish), beginning with an initial mailing that includes a survey web link as well as a QR code to the survey and a personalized access code. A consent form (**Attachment 4e** for English, **Attachment 4f** for Spanish) will also be included in this initial mailing. Caregivers will receive the same series of follow-up communications as

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Wave 1 and Wave 2 Survivor Survey participants, each two weeks apart: reminder postcard (**Attachment 4g** for English, **Attachment 4h** for Spanish); follow-up mailing (**Attachment 4g** for English, **Attachment 4h** for Spanish); paper survey mailing (**Attachment 4g** for English, **Attachment 4h** for Spanish); phone reminder (**Attachment 4g** for English, **Attachment 4h** for Spanish). The paper Caregiver Survey (**Attachment 4b** for English, **Attachment 4d** for Spanish) contains 63 questions in English and in Spanish. The paper survey responses will be electronically scanned and saved to the contractor's secure project folder.

At the end of the Wave 1 and Caregiver Surveys, participants will be able to volunteer for a one-hour interview in which they can elaborate on their experiences accessing care as well as providing support to the care recipient (the latter is for caregivers only). The interviews will be conducted in English. The survivor interview guide (**Attachment 5a**) has 9 questions and the caregiver interview guide (**Attachment 6a**) has 9 questions. We will provide a consent form to individuals who were previously diagnosed with cancer (**Attachment 5b**) and caregivers (**Attachment 6b**) prior to the interviews. Individuals who do not respond to our initial email (**Attachment 5c** and **Attachment 6c**) will get a follow-up email within two weeks (**Attachment 5c** and **Attachment 6c**). Individuals who respond and schedule an email will receive a reminder email in advance of their interview (**Attachment 5c** and **Attachment 6c**). Finally, we will send a thank you email (**Attachment 5c** and **Attachment 6c**) after the interview.

Representatives from advocacy organizations will be contacted through the contractor and subcontractor's personal and professional networks. These individuals will receive an introductory email (**Attachment 7c**) inviting them to participate in a one-hour focus group to discuss the barriers to care – and potential solutions – that their clients face. This email will include a copy of the consent form (**Attachment 7b**). The focus group guide (**Attachment 7a**) contains 7 questions. Individuals who do not respond to our initial email will get a follow-up email (**Attachment 7c**). Individuals who respond and schedule a focus group will receive a reminder email in advance of their focus group (**Attachment 7c**). Finally, we will send a thank you email (**Attachment 7c**) after the focus group.

Staff trained in the appropriate qualitative and/or quantitative research methods will conduct all analyses. Information will be stored on a secure shared drive with access limited to project team members. For the Wave 1, Wave 2, and Caregiver Surveys, CDC will not have access to any file that links the names and addresses of participants with their unique participant ID#.

B3. Methods to Maximize Response Rates and Deal with No Response

Multiple strategies will be used to maximize response rates. Drafts of the survey data collection instruments as well as the semi-structured interview protocol and focus group protocol were shared with internal CDC team members, who have expertise in cancer studies and cancer care, for review and feedback throughout the development process.

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The Web-based mode of surveys was selected as the initial survey mode to minimize burden. The surveys will take the respondent approximately 15-20 minutes to complete (Wave 1 Survivor Survey – 20 minutes; Wave 2 Survivor Survey – 20 minutes; Caregiver Survey – 15 minutes), and the surveys will be accessible across multiple browsers (e.g., Internet Explorer, Google Chrome, Mozilla Firefox) and devices (e.g., smartphones, tablets, laptops). The introductory letter for each of the three surveys will include a QR code to the survey, to minimize burden of typing in the survey URL (**Attachments 2g and 2h** for English and Spanish letters in the Wave 1 Survivor Survey, **Attachments 3g and 3h** for English and Spanish letters in the Wave 2 Survivor Survey, and **Attachments 4g and 4h** for English and Spanish letters in the Caregiver Survey). The introductory letters will also reference the Centers for Disease Control (CDC) and the cooperation of the respective state's cancer registry, to lend credibility to the survey invitation. Individuals who do not complete a survey online will receive three mailed reminders (**Attachment 2g** for English communications related to Wave 1 Survivor Survey; **Attachment 2h** for Spanish communications related to Wave 1 Survivor Survey; **Attachment 3g** for English communications related to Wave 2 Survivor Survey; **Attachment 3h** for Spanish communications related to Wave 2 Survivor Survey; **Attachment 4g** for English communications related to Caregiver Survey; and **Attachment 4h** for Spanish communications related to Caregiver Survey), including a final mailing with a paper survey and pre-paid business reply envelope. A final reminder phone call (**Attachment 2g** for English phone script and **Attachment 2h** for Spanish phone script in Wave 1 Survivor Survey; **Attachment 3g** for English phone script and **3h** for Spanish phone script in the Wave 2 Survivor Survey; and **Attachment 4g** for English phone script and **4h** for Spanish phone script in the Caregiver Survey) will be provided, with an offer to complete the survey over the phone if desired. Survey participants will all be offered a \$40 incentive to help increase response rate.

Representatives from cancer patient/survivor advocacy groups that serve individuals on one of the participating states (California, North Carolina, and Texas) have offered to promote participation in the survey amongst their constituents to help increase response rate.

Virtual interviews and focus groups are being employed to collect qualitative data without the costs and respondent burden associated with traditional face-to-face site visits.

Additionally, we will provide a tailored, recognizable email address (e.g., CDC_CancerSurvey@rti.org) and toll-free line (staffed by project team members who are bilingual) in all communication materials and on the introductory pages of the web-based and paper surveys, so that project staff are readily accessible for questions or trouble-shooting.

Despite these multiple approaches to increase response rate, we do not expect to achieve an 80% response rate. We will conduct non-response analysis to identify the odds of responding to the survey.

B4. Tests of Procedures or Methods to be Undertaken

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To ensure that items and responses can be understood by participants on the Web-based and paper surveys as well as the semi-structured interview protocol and focus group protocol, CDC, contractor and subcontractor staff who have social determinants of health expertise and cancer care expertise reviewed all data collection instruments. Edits were based on feedback provided by subject matter experts.

The Web-based surveys were tested to ensure accessibility across multiple browsers and devices and to confirm that content and skip patterns were programmed correctly. Additionally, the contractor conducted cognitive interviews to test the English and Spanish versions of the web-based surveys for clarity and comprehensiveness. Participant feedback was shared with CDC and final edits were made based on their decisions.

Once the surveys were finalized, contractor staff tested the length of time needed to complete the web-based and paper surveys in English and Spanish. According to the results from these tests, the average time to complete:

- the Web-based Wave 1 Survivor Survey in English (**Attachment 2a**) was approximately 20 minutes, and the estimated time range for actual respondents to complete the instrument is 17-23 minutes;
- the Web-based Wave 1 Survivor Survey in Spanish (**Attachment 2c**) was approximately 20 minutes, and the estimated time range for actual respondents to complete the instrument is 17-23 minutes;
- the paper Wave 1 Survivor Survey in English (**Attachment 2b**) was approximately 20 minutes, and the estimated time range for actual respondents to complete the instrument is 17-23 minutes;
- the paper Wave 1 Survivor Survey in Spanish (**Attachment 2d**) was approximately 20 minutes, and the estimated time range for actual respondents to complete the instrument is 17-23 minutes;
- the Web-based Wave 2 Survivor Survey in English (**Attachment 3a**) was approximately 20 minutes, and the estimated time range for actual respondents to complete the instrument is 17-23 minutes;
- the Web-based Wave 2 Survivor Survey in Spanish (**Attachment 3c**) was approximately 20 minutes, and the estimated time range for actual respondents to complete the instrument is 17-23 minutes;
- the paper Wave 2 Survivor Survey in English (**Attachment 3b**) was approximately 20 minutes, and the estimated time range for actual respondents to complete the instrument is 17-23 minutes;
- the paper Wave 2 Survivor Survey in Spanish (**Attachment 3d**) was approximately 20 minutes, and the estimated time range for actual respondents to complete the instrument is 17-23 minutes;
- the Web-based Caregiver Survey in English (**Attachment 4a**) was approximately 15 minutes, and the estimated time range for actual respondents to complete the instrument is 12-18 minutes;

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- the Web-based Caregiver Survey in Spanish (**Attachment 4c**) was approximately 15 minutes, and the estimated time range for actual respondents to complete the instrument is 12-18 minutes;
- the paper Caregiver Survey in English (**Attachment 4b**) was approximately 15 minutes, and the estimated time range for actual respondents to complete the instrument is 12-18 minutes;
- the paper Caregiver Survey in Spanish (**Attachment 4d**) was approximately 15 minutes, and the estimated time range for actual respondents to complete the instrument is 12-18 minutes;

B5. Individuals Consulted on Statistical Aspects and Individuals Collecting and/or Analyzing Data

DCPC assumes oversight responsibility for the development of the overall assessment design, data collection, and analysis. Sahar Zangeneh, RTI Project Director, is the person primarily responsible for collecting the information and interpreting the findings. The individuals responsible for overseeing instrument design, data collection, and analysis are the following:

Name	Contact Info	Organization	Role
Nikie Sarris Esquivel	nsarris@rti.org	RTI	Data collection designer (online and paper surveys)
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			programmer
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