

**Attachment 4e.**  
**Caregiver Survey**  
**Consent Form**

### **Key Information**

*This research study, led by RTI International and Implenomics on behalf the Centers for Disease Control and Prevention (CDC), looks at the problems that individuals who had cancer or are living with cancer may face while getting cancer care. We are also looking at the barriers their caregivers may face. You can answer the survey online or on paper in English or Spanish. The survey takes about 15 minutes, and you'll have up to 2 weeks to do it. Your participation is optional. If you participate in the survey, you will receive a \$40 check or gift card as a thank you. There are no benefits to you. There are protections in place to keep your data private and safe.*

*This consent form is for your records.*

## **Consent to Participate in a Study – Caregiver Survey**

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

Principal Investigator: Sahar Zangeneh, PhD, RTI International

Study Sponsor: U.S. Centers for Disease Control and Prevention (CDC)

### ***What Is the Study About?***

The study looks at the problems people face in receiving cancer care. The survey asks about barriers experienced at different times, like when they are screened, diagnosed, treated, and after treatment. It will improve our understanding of the cancer care experience, and how experiences may vary for different populations. You were originally invited to complete the survey because you had colorectal, female breast, or cervical cancer in 2021, when you were between 21 and 75 years old. You are now being invited to complete a follow-up survey, which builds upon the information you shared previously. If you choose to be in this study, you will be joining about 1,200 other people that we anticipate will complete the follow-up survey.

### ***Who Is Leading the Study?***

The person leading this study is Dr. Sahar Zangeneh (Principal Investigator) of RTI International. This study is being funded by the Centers for Disease Control and Prevention (CDC). Implenomics, International a woman-owned small business that is focused on improving healthcare delivery in the United States, is also supporting this study.

## ***What Is the Purpose of This Study?***

The purpose of this study is to learn about the types of problems that individuals who had cancer or are living with cancer and their caregivers may face. We want to know what keeps them from getting the right care. These problems could include not having health insurance, trouble making appointments, or not having a way to get to the doctor. The survey you completed previously contained questions about your background and your experiences with cancer screenings, diagnosis, and treatment. This follow-up survey will focus on your experiences during treatment and post-treatment phases. It will examine your quality of life, health care, and factors that affected your well-being during this period.

## ***Do I Have to Take Part in this Study?***

No, you do not have to join this study if you do not want to. It's your choice. Your decision will not affect any benefits or rights you have. If you do start the survey, you can stop at any time. If you fill out the survey but later change your mind, you can ask to have your answers removed by contacting CDC\_CancerSurvey@rti.org or 1-833-997-2714, and we will permanently delete your survey responses.

## ***Where Is the Study Going to Take Place and How Long Will It Last?***

We are asking individuals who had cancer or are living with cancer in California, North Carolina, and Texas to answer a survey about their experiences. The survey will be available online and on paper in both English and Spanish. The survey takes about 15 minutes to complete, and you will have up to 2 weeks to do it.

## ***What Will I Be Asked to Do?***

You will be asked to answer questions about your life, health, and cancer care. You can answer online or on paper in English or Spanish. If you do not complete the online survey after the invitation letter, we will send a folded and sealed postcard reminder, a letter reminder, and then a paper copy of the survey with a prepaid business reply envelope for you to return the completed survey. You may also receive a telephone reminder to complete the online or paper survey. You will receive a \$40 check or gift card if you finish the survey.

## ***What Are the Possible Risks and Discomforts?***

Joining this study has minimal risks. Some of the questions on the survey may be upsetting, but you don't have to answer them. Protections are in place to keep your data as safe as possible.<sup>1</sup>

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<sup>1</sup> Including, but not limited to, storing data on secure servers, password protecting data files, and keeping names and addresses separate from all other respondent data.

## ***Will I Benefit from Taking Part in This Study?***

You will not personally benefit from taking part in this study.

## ***What Will It Cost to Participate?***

There are no costs associated with participating in this study.

## ***Will I Receive Any Payment or Reward for Taking Part in this Study?***

You will receive a \$40 check or gift card for finishing the survey.

## ***Who Will See the Information I Give?***

Only select project staff at RTI and Implenomics will be able to connect the data you provide with your name or personally identifiable information. We will keep your name separate from your answers and use a random ID to label your answers. Your name and any information linked to your name will be kept in a separate, password-protected file.

Your answers will be combined with information from other participants in the study for reports. Your personal answers will not be identified in any reports or presentations. Your contact information will never be shared.

## ***Can My Data Be Kept and Used for Other Studies?***

Yes, your data can be kept. Your answers might help other researchers, advocacy groups, and policy makers in the future, but your name won't be used, and there are protections in place to keep your data private and safe. However, data will not be shared with others for future use without requiring a Data Use Agreement (DUA) that strictly outlines the research question to be answered and how the data can be used. We will not ask for your additional informed consent for these studies.

## ***Can My Taking Part in the Study End Early?***

You can stop the survey anytime. If you already answered part of the survey but don't want your answers used, please contact us at [CDC\\_CancerSurvey@rti.org](mailto:CDC_CancerSurvey@rti.org) or 1-833-997-2714, and we will permanently delete your survey responses.

## ***What If I Have Questions?***

Please ask any questions by contacting [CDC\\_CancerSurvey@rti.org](mailto:CDC_CancerSurvey@rti.org) or 1-833-997-2714.

If you have questions about your rights as a research participant, contact the RTI Office of Research Protection at 1-866-214-2043.

## **Certificate of Confidentiality**

This project is funded by the Department of Health and Human Services (DHHS), and specifically the Centers for Disease Control and Prevention (CDC) and holds a Certificate of Confidentiality (CoC) that offers additional protections for your identifiable research information and records. The most important protection is that members of the research team cannot be forced to disclose or provide any of your private identifiable information in any Federal, State, or local civil, criminal, administrative, legislative, or other proceeding unless you provide permission. Disclosure of your research information may only occur in limited specific instances, such as a hard copy survey not being shredded immediately after data entry, or an identifier being accidentally left in the cleaned data output. By continuing on to the survey online, or completing and returning the paper survey, you are confirming your consent to participate in the research.