

Attachment 6b.
Caregiver Interview
Consent Form

Key Information

This research study, led by RTI International and Implenomics on behalf the Centers for Disease Control and Prevention (CDC), will collect and analyze data to learn about the social and economic barriers that individuals diagnosed with colorectal, breast, and cervical cancer face at each stage of the cancer care continuum. In our survey, you indicated that you would be interested in volunteering for a 45-60-minute online interview. You are one of 20 individuals who has been selected to participate in the interviews we are conducting. Your participation is voluntary. There are no direct benefits to you. There are protections in place to keep your data private and safe. We will not quote you by name.

This consent form is for your records.

Consent to Participate in a Study – Interview with Individuals Diagnosed with Cancer

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 while getting cancer care. The interview will ask about people's ability to get the right care 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 are being invited to participate in this study because you had colorectal, female breast, or cervical cancer in 2021 and because you expressed interest in participating in the interview. If you take part in this interview, your responses will be combined with those of other participants.

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, 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 goal of this study is to learn about the types of problems that individuals who had cancer or are living with cancer may face. We want to know what barriers individuals face in 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.

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 interview, you can stop at any time. If you complete the interview 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 responses.

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

We are asking twenty individuals who had cancer or are living with cancer in California, North Carolina, and Texas, who completed a survey about their experiences from cancer screening through treatment, to participate in an interview. The interview will be conducted online via Zoom in English. The interview should take no more than 60 minutes to complete.

What Will I Be Asked to Do?

You will be asked to complete a 45-60-minute interview with questions about your background (e.g., employment, income, area of residence) and experiences with cancer health care services. The interview will be conducted online via Zoom in English. With your permission, we would like to record the Zoom session to back up our notes. The recording will include both audio and video unless you turn your camera off. If you prefer not to be recorded on video, please feel free to turn off your camera at any time during the session. Turning off your camera does not preclude you from participating in the study, and you will still be audibly recorded if you have provided permission.

What Are the Possible Risks and Discomforts?

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

¹ 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 participating in this interview.

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 not receive any payment or reward for taking part in this interview.

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.

We will destroy all your personal information and interview answers within three years of the completion of this study, unless we need to keep it for legal or scientific reasons.

Can My Taking Part in the Study End Early?

You can stop the interview anytime. If you already answered part of the interview but don't want your answers used, please contact us at CDC_CancerSurvey@rti.org or 1-833-997-2714, and we will permanently delete your interview responses.

What If I Have Questions?

Please ask any questions by contacting 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 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 transcript not being shredded immediately after data analysis, or an identifier being accidentally left in the cleaned data output.