

**Attachment 7b.**  
**Patient and Survivor Advo Org Focus Group**  
**Consent Form**

### **Key Information**

*This research study, led by RTI International and Implenomics on behalf of the Centers for Disease Control and Prevention (CDC), will collect information from individuals living with cancer, their caregivers, and cancer care advocates. You are one of 16 cancer care advocates who has been selected to participate in a 45–60-minute online focus group. 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 – Advocacy Group Representatives**

### **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 is about the barriers to health care at each step of the continuum and the extent to which they differ across affected populations. We are aiming to identify barriers faced by individuals diagnosed with colorectal, female breast, and cervical cancer along the cancer care continuum: screening, diagnosis, treatment, and post-treatment/survivorship. We are also exploring barriers that caregivers may face when providing care during the care recipient's treatment and post-treatment/survivorship, as well as their perceptions of the barriers that their care recipients faced during treatment. The focus group will improve our understanding of the cancer care experience, and how experiences may vary for different individuals. You were invited to participate in this study because your organization, [Organization name], provides services and support both to individuals who had cancer or are living with cancer, as well as to their caregivers. The focus group will explore your expertise and experience as a cancer care advocate, focusing much of our discussion on hearing about the potential barriers to accessing cancer treatment and follow-up care that your clients encounter. If you take part in this focus group, you will be one of 16 people to do so.

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

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

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

The goal of this study is to learn about the experiences of individuals diagnosed with colorectal, female breast, and cervical cancer and their caregivers, and any barriers to treatment or follow-up care. For example, we are interested in learning how barriers to the provision of care may impact the patient's physical, financial, or emotional well-being. This focus group will improve our understanding of the cancer care experience, and how experiences may vary for different individuals.

## ***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.

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

We are asking 16 cancer care advocates to participate in the focus groups. Each focus group will be conducted online via Zoom in English. The focus group should take no more than 45-60 minutes to complete.

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

You will be asked to participate in a 45–60-minute focus group about topics including your experience as a cancer care advocate and barriers to care that cancer patients may face from screening through diagnosis, cancer treatment and/or follow-up care. The focus group 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 focus group questions 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 participating 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 not receive any payment or reward for taking part in this focus group.

## ***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. We ask all focus group participants to keep everything discussed in the group confidential. While we cannot guarantee others will follow this request, we expect participants to not disclose identities of any participants or repeat information shared to anyone outside this group.

## ***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 focus group 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 focus group anytime. If you already answered part of the focus group 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 focus group 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 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.