

CONSENT: CER Registry – An Online Survey Research Study to Understand the Experiences of Those Impacted By a Cancer Diagnosis

What is the study about?

The goal of this research study is to learn more about the experiences and needs of people who have been diagnosed with cancer or who have been a friend or family caregiver for someone diagnosed with cancer. The information from the study can be used to raise awareness of the challenges faced by people affected by cancer, guide policy aimed at increasing quality of care, and develop programs and services to meet patient and caregiver needs and improve their quality of life.

Who is conducting the study?

This study is being conducted by the Cancer Support Community (CSC), which is the largest professionally led nonprofit network of cancer support worldwide. The Cancer Support Community is dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community.

Do I have to take part?

Taking part is voluntary. You do not have to take part in this study. Your decision will not affect the services you receive from your insurance, doctors, or from CSC. The alternative is not to take part. You can choose to not take part or to withdraw from this study without penalty or loss of benefits to which you are otherwise entitled.

Who can take part in this study?

To take part in this study, you must live in the United States, a U.S. territory, or Canada and be at least 18 years of age, unless you live in the Canadian provinces of British Columbia, New Brunswick, Newfoundland and Labrador, Northwest Territories, Nova Scotia, Nunavut, or Yukon, in which case you must be 19 years of age. You must also be able to read and understand English. You must have been diagnosed with cancer at any point in your life or have been a friend or family caregiver for someone with cancer.

If you do not meet these eligibility requirements, the information you provided will be removed and you will not be asked to take part in future Registry surveys.

What happens if I say ‘yes’?

If you say yes, you will be registered to take part in a study called the Cancer Experience Registry (the “Registry”). First, you will fill out an initial survey about your experiences with cancer, which should take about 35 minutes to complete. After completing the initial survey, you may become eligible to receive invitations for follow-up Registry surveys at 6, 12, 18, and 24 months following completion of the baseline survey to help understand changes in the cancer experience over time as well as other Registry surveys on emerging topics in cancer care. All follow-up Registry surveys will take about 15-20 minutes to complete.

To provide additional opportunities to elevate your voice and experiences, you may also be contacted by CSC about other research opportunities, programs, or supportive services. Basic information, such as cancer diagnosis or treatment information, may be used to determine whether various opportunities are applicable to you. Participation in additional opportunities is voluntary. You will be eligible to receive opportunities indefinitely unless you choose to opt out by clicking unsubscribe at the bottom of any invitation email or by emailing the research team at registry@cancersupportcommunity.org. Data from publicly available data sources may also be linked to your responses.

A description of this clinical trial will be available on <http://www.ClinicalTrials.gov>, as required by U.S. Law. This Web site will not include information that can identify you. At most, the Web site will include a summary of the results. You can search this Web site at any time.

Will I be paid?

You will not receive financial compensation for the initial Registry survey.

What are the costs?

There is no cost to you to take part in the Registry except the time it takes to complete the surveys. Internet access and data usage costs may apply.

Is there any risk to taking part in this study?

You may find some of the questions sensitive or uncomfortable to answer. You can skip any question that you don't want to answer. You can stop participating at any time without losing the services you receive from your insurance, doctors, or from Cancer Support Community. If you need social and/or emotional support, you can call the CSC's toll-free Cancer Support Helpline at 888-793-9355, or sign-up for free services offered at www.cancersupportcommunity.org.

While the risk is low, there is also a risk of loss of privacy, which is explained in the "How will my privacy be protected?" section below.

What is the benefit of taking part?

There is no direct benefit to you for taking part in this study. Your participation will be used to better understand the needs of people who have been diagnosed with cancer or who have been a friend or family caregiver for someone with cancer. The results from this study will raise awareness about challenges faced by people affected by cancer, and will be used to develop policies and programs to meet their needs and improve their long-term quality of life. Regardless of your participation in the survey, you will also have access to summary reports and educational resources.

How will my privacy be protected?

Your participation in the Registry will be kept as confidential as possible. Your data are stored online in the Voxco system, which is completely encrypted, as well as GDPR Compliant, Privacy Shield Certified, TCPA Compliant, and SOC2 Compliant. Data are only downloaded from Voxco onto CSC's company servers, which operate on OneDrive, which has at-rest and in-transit encryption as standard for all users and file types. Only members of the research team will be able to access your contact information. We will do our best to protect the confidentiality of all the information you provide, but no one can guarantee complete confidentiality for data that are sent over the Internet.

Regulatory agencies and the Institutional Review Board (IRB) – a team of reviewers that makes sure the rights and welfare of research participants are protected – may also have access to study records for monitoring purposes. These records may have names linked to participant ID numbers, but will be stored on secure servers, and the datasets used in analysis will not include your name or identifiable information.

The results of this project may be shared with partner organizations or funders, appear in scientific journals, or presented at professional meetings; however, your name and other identifying information will not be shared.

What if I have questions about the study or my rights as a research participant?

If you have any questions about this study, would like offer input, or believe you have been harmed as a result of taking part in the Registry, or have questions about your rights as a research participant you should contact Principal Investigator Erica Fortune, PhD, at 1-202-659-9709 or registry@cancersupportcommunity.org.

If you have questions about your rights as a research participant or if you have questions, concerns or complaints about the research, you may contact an impartial reviewer, Salus IRB, at 1-800-472-3241 or email at subject@salusirb.com. The Salus study reference number is 23044.

This makes sense to me, so what do I do now?

Completion of any of the surveys implies that you have read the information in this form and consent to take part in this research study. By agreeing to take part in this study and providing online consent, you do not give up any of your legal rights.

By clicking "YES" below, you agree to take part in this research study and confirm that you live in the United States, a U.S. territory, or Canada, are at least 18 years of age (or at least 19 years of age if you live in the Canadian provinces listed above), are proficient in English, and were diagnosed with cancer at some point in your life or have been a friend or family caregiver for someone with cancer.

- Yes, I agree to participate in this research study and confirm that I am eligible for this study
- I do not want to participate in this research study, or I am not eligible for this study.