



What is the study about?

You are being asked to participate in a research study to understand the needs of people who have been diagnosed with cancer or who have provided care to someone with cancer (i.e., informal or family caregiver). The information from the study will improve understanding of the needs of cancer survivors and those living with the diagnosis, raise awareness of the challenges of people affected by cancer, and develop programs and services that will address the needs and improve the long-term quality of life of people impacted by cancer.

Do I have to participate?

No, participation is voluntary. You do not have to participate in this study. Your alternative is not to take part. Your decision will not affect the services you receive from your health care facility. If you choose not to participate in the study or withdraw, you will still be able to receive any services provided by your health care facility and the Cancer Support Community.

What happens if I say ‘yes’?

If you say yes, you will be registered to participate in the survey component of the Cancer Experience Registry (the “Registry”). After saying yes, you may access surveys to answer questions and share your experience over time. The time it takes to complete a survey depends on the amount of questions.

What will this cost me and will I get paid to participate?

There is no cost or payment to take part in the Registry surveys.

What is the benefit of participating?

You may not receive a direct benefit from being in this study. Your participation will be used to support greater understanding of the needs of cancer survivors and those living with the diagnosis, raise awareness of the challenges of people affected by cancer, and develop programs and services that will address the needs and improve the long-term quality of life of people impacted by cancer. Collective reports may be provided to collaborating and contracted organizations and sponsors to understand quality of care or member needs. The results of the data gathered from the surveys may be published in scientific journals or presented at professional medical or psychological meetings; however, names will not be used. You will be able to view summary responses from others in the Registry who have participated in the surveys. You will also have access to summary reports and educational resources.

Is there any risk to participating in the study?

It is possible that you may find answering some of the questions upsetting. You don’t have to answer any question that you don’t want to answer. You can choose not to take part or leave the study at any time without penalty or loss of benefits you are entitled. In the event you need social and/or emotional support, the Cancer Support Community has a toll-free helpline, which you can access over the phone at 888-793-9355, and free services, which can be accessed online at www.cancersupportcommunity.org. There is also a risk of loss of privacy.

Could I be removed from participating in the study?

You will be removed from the study if it is determined that you do not meet the eligibility requirements. You must be at least 18 years of age and diagnosed with cancer at any point in time in your life, or have been a family caregiver or informal caregiver (i.e., a relative or friend) for someone diagnosed with cancer, and must be able to read and understand English.

How will my identity be protected?

There is a minimal possibility of loss of privacy or confidentiality. However, research records will be kept as private as possible according to all local, state, and federal laws. Only trained members of the research team will be able to link contact information to survey responses. This link will be kept as secure and confidential as possible. If you are enrolling in the Cancer Experience Registry through a third-party site (e.g., a hospital), designated staff members at that site may be granted access to your name, date of birth, and email address. They may also be allowed to see whether you have created a user account with the Registry or started or completed Registry surveys, but will not see any other individual personal information or survey responses. Your email will be obtained for purposes of completing the registration process and to provide you with updates about the Registry and its findings. You may be sent reminders to complete your registration or survey participation. You may also be contacted by Cancer Support Community about additional research, programs and services, or other related opportunities; you may opt out of these communications at any time. The research staff will have access to study records. The Institutional Review Board (IRB) may also have access to study records.

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

If you have any questions about this study or would like to report research related harm, you should contact Linda House at 1 (202) 650-5382 or email linda@cancersupportcommunity.org. If you have questions about your rights, would like to offer input, or have any complaints that you feel you cannot take to Ms. House, you may call an impartial reviewer, Ethical & Independent Review Services (E&I) IRB at 1-(800) 472-3241, or email at subject@eandireview.com. Reference study # 16036. E&I is a group of people that looks out for the rights and welfare of research participants.

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

If you agree to participate in this study, you will need to provide consent. Please do not provide your consent unless you have had a chance to ask questions and have received acceptable answers to all of your questions. A copy of this consent form will be available to you.

Yes, I agree to participate in this research study.

A copy of the consent can be downloaded here