

**Cancer Experience Registry: An Online Research Study to Understand the Experiences of Cancer Patients and Caregivers**

Clinical Trials Registration Number: NCT02333604

Date : October 8, 2021

## **CONSENT: Baseline Patient and Caregiver Questionnaire**

### **What is the study about?**

The goal of this study is to learn more about the experiences and needs of people who have been diagnosed with cancer or who have been a family caregiver or informal caregiver (i.e., a relative or friend) 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, 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?**

No, 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 the Cancer Support Community.

### **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 family caregiver or informal caregiver to 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 be asked to fill out an initial survey about your experiences with cancer, which should take less than an hour to complete. After completing the initial survey, you may become eligible to receive invitations for follow-up Registry surveys to understand changes in the cancer experience over time as well as other Registry surveys on emerging topics in cancer care. Many of these other surveys will provide financial compensation.

To provide additional opportunities to elevate your voice and experiences, you may also be contacted by the Cancer Support Community 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 these additional opportunities is voluntary, and you may opt out of these communications at any time. Data from publicly available data sources may also be linked to your responses.

### **What are the costs and risks of taking part?**

There is no cost to you to take part in the Registry except the time it takes to complete the surveys.

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 the Cancer Support Community. If you need social and/or emotional support, you can call the Cancer Support Community’s toll-free Cancer Support Helpline at 888-793-9355, or sign-up for free services offered at [www.cancersupportcommunity.org](http://www.cancersupportcommunity.org). While the risk is low, there is also a risk of loss of privacy, which is explained in the section below.

**What is the benefit of taking part?**

Your participation will be used to better understand the needs of people who have been diagnosed with cancer or who have been a family caregiver or informal caregiver to 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 is confidential. 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. The NORC Institutional Review Board (IRB) and Cancer Support Community may review records related to this research study. 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 names or identifiable information. 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.

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

If you have any questions about this study or believe you have been harmed as a result of taking part in the Registry, you should contact Melissa Miller, PhD, MPH, at 202-650-5373 or [registry@cancersupportcommunity.org](mailto:registry@cancersupportcommunity.org). If you have questions about your rights as a research participant, please contact the Respondent Care Center at NORC at the University of Chicago by calling 1-866-856-6672 or emailing [surveyhelp@norc.org](mailto:surveyhelp@norc.org). You can also contact the NORC IRB at (866) 309-0542 or email [IRB@norc.org](mailto:IRB@norc.org). The IRB reference number for this study is 21-07-371.

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

Completion of the survey implies that you have read the information in this form and consent to take part in this research study. A link to download a copy of this consent form will be emailed to you. Please keep this form for your records or future reference.

By clicking “YES” below, you agree to take part in this research study and confirm that you 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 family caregiver or informal caregiver to 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. [\[exit survey\]](#)