**Experiences of Cancer Patients in Transition Study**

**Frequently Asked Questions**

*If you received an invitation to participate in the survey, please visit* [*www.cancertransitionsurvey.ca*](http://www.cancertransitionsurvey.ca) *to complete the survey online.*

About this document:

This document is intended for the provincial study teams who may receive questions from colleagues or the general public about the *Experiences of Cancer Patients in Transition Study.*

About the study:

Why is this study taking place?

When cancer treatment ends, patients and survivors transition from speciality oncology care (e.g., where they had surgery, chemotherapy, radiotherapy, etc.) back to the broader health care and support system (e.g., to their family doctor or in primary care settings, community-based care, and rehabilitation services). This transition is often met with questions about what happens next, what changes, and where to go to seek help. The Canadian Partnership Against Cancer and [insert partner name] are looking to inform recommendations to improve quality of life and ensure a more seamless transition for cancer patients and survivors as they return to the broader health system.

1. What organizations are participating in this study?

The Canadian Partnership Against Cancer works with partners across the country to reduce the incidence of cancer, lessen the likelihood of Canadians dying from cancer and enhance the quality of life for those living with cancer. For the *Experiences of Cancer Patients in Transition* study, the Partnership is collaborating with 10 provinces. Study partners include the BC Cancer Agency, CancerControl Alberta, Saskatchewan Cancer Agency, CancerCare Manitoba, Cancer Care Ontario, Ministère de la Santé et des Services sociaux du Québec, Institute de la statistique du Québec, New Brunswick Cancer Network, Cancer Care Nova Scotia, Health PEI and Eastern Health Cancer Care Program.

How will the results be used?

The results of the survey will be analysed and recommendations will be made to improve the way cancer care, primary care, and community services work together to provide follow-up and supportive care.

1. Why is the term ‘cancer patients and survivors’ used throughout the survey materials and not just ‘cancer survivor’ or ‘cancer patient’?

It was decided that the term ‘cancer patients and survivors’ would be used throughout all communications about the Study. That way, survey respondents could self-identify to either term (‘patient’ or ‘survivor’) based on their own personal experiences and preferences.

What is the Canadian Partnership Against Cancer (the Partnership)?

The Partnership works with cancer control partners from across Canada to achieve our shared goal of a future in which fewer Canadians get cancer, fewer die from it and those living with the disease have a better quality of life ([www.partnershipagainstcancer.ca](http://www.partnershipagainstcancer.ca)).

Who is this survey actually from?

Ipsos, an independent survey agency, is administering the survey on behalf of the Canadian Partnership Against Cancer and [insert name of organization] has invited you to take part.

The Partnership works with cancer control partners from across Canada to achieve our shared goal of a future in which fewer Canadians get cancer, fewer die from it and those living with the disease have a better quality of life ([www.partnershipagainstcancer.ca](http://www.partnershipagainstcancer.ca)).

What is Ipsos?

Ipsos is the third largest research firm in the world. The Ipsos team crosses North America including Toronto, Ottawa, Calgary, Vancouver, Chicago, New York, and Washington, D.C. They conduct strategic research in partnership with clients from government, public, corporate, and not-for-profit sectors. Specifically, they have extensive experience within the health care sector and have developed strategic research programs for health-care organizations that focus on health-care policy, service delivery and patient experience measurement.

Who designed the questions?

The survey was designed by the Transitions Study Project Team that is comprised of a panel of experts, health care providers, patients and families, provincial cancer agencies, researchers from Ipsos, and the Canadian Partnership Against Cancer. The Principal Investigators from the provincial cancer agencies and programs and other stakeholders (including academics, medical and other health care specialists, and patients) were consulted and provided feedback during survey development.

**Confidentiality and data protection:**

How did you get my name and address?

You are in the [insert provincial cancer agency name]’s cancer patient registry and invited to take part in this study because you completed your primary cancer treatment between one and three years ago.

Do you have access to my health data?

The [insert provincial cancer agency name] does have access to some data about your cancer treatments and may use it in combination with your survey responses for analysis. No one else involved in this study has access to any information about you; not your name, address or anything else about your health. Only anonymous statistical results will be provided to the Canadian Partnership Against Cancer.

Why are you asking about my personal information?

You will be asked questions about your age, gender, education, language, household size, and income so that we can better understand the population being surveyed and to analyze the responses of different groups. For example, the team will be able to analyze the data by different demographic factors such as age group to determine if responses between these groups are different in any way. Demographic data is very important to the research. We encourage you to complete these questions.

How is my doctor/nurse practitioner/oncologist involved in this survey?

Your doctor/nurse practitioner/oncologist is not involved in the survey and will not be made aware of your participation in the study, unless you share this information with them directly. There is no way to link your responses to any specific health care provider. Choosing to participate or declining to answer survey questions will have no connection to your specific care team and will not influence your cancer care in any way.

Your feedback is being sought as a way to try to improve the overall integration between cancer care and other sectors of the health care system providing follow-up and supportive care. You were eligible and invited to take part in the survey, because you completed your primary cancer treatment between one and three years ago.

Will my doctor/nurse practitioner/oncologist see my answers to this survey?

No, your doctor/nurse practitioner/oncologist will not see the answers to your survey. No one outside of the study team at [insert organization name] will know whose surveys have been completed. Choosing to participate or not participate in this study or declining to answer survey questions will not in any way affect the care you receive.

Will I be identifiable in the results?

No, we request that you do not write your name or where you live on the survey or on the return envelope to keep your results anonymous. Any identifiable individual answers will not be seen by anyone at Ipsos or the Canadian Partnership Against Cancer. Only anonymous statistical results will be provided to the Canadian Partnership Against Cancer.

Taking part:

Why was I sent a survey?

As someone who had been diagnosed and treated for cancer, you have first-hand experience about the kinds of supports patients need as they finish their cancer treatment and make the transition back to their lives after cancer treatment.

Your name was pulled from the local cancer registry by [insert provincial cancer agency name]. The local cancer registry is a database where the names of all individuals who have been diagnosed with cancer in your province are kept. You were eligible to take part in this survey because you completed your cancer treatment between one and three years ago.

Why haven’t I received a survey? How do I get one?

The survey has been sent to individuals who completed their primary cancer treatment between one and three years ago. This group of individuals was selected through a specific study procedure in order to be certain we have a representative sample of individuals. Unfortunately, we cannot send surveys to people who have not been selected through our study protocol or procedures to take part in the study.

I am completing cancer treatment at the moment, should I still complete the survey?

For this survey, we ask you to think only about the time period after completing cancer treatments such as surgery, chemotherapy, radiation therapy, etc. If you are currently going through cancer treatment for a second cancer, please think about the follow-up care you received after completing cancer treatment for your first cancer.

It’s been a long time since I completed cancer treatment, should I still complete the survey?

Yes, please complete the survey. We are gathering feedback to better understand the experiences of people who have completed cancer treatment. Even if your treatment was a few years ago, we would still like to know about your experience of follow-up cancer care.

Who should I contact if I do not want to take part?

Taking part is completely voluntary. We hope you will take part and complete the survey as this will give us the best possible picture of people’s experiences of support and care after they completed cancer treatment. If you do not wish to take part, you do not have to do anything else. You may still receive a reminder letter from [insert provincial cancer agency name], which you may also ignore. If you wish to have your name and address removed from the reminder mailings, please contact [insert provincial cancer agency name and contact information].

Completing the survey:

How do I complete the survey?

There are two ways you can complete the survey. You can complete the questions online or via the paper survey you’ve been sent in the mail.

Do I have to answer all the questions?

Answering these questions is completely voluntary. It is entirely your choice what questions you answer. However, we hope you will take part and complete the survey, as this will give us the best possible picture of people’s experiences. There are some questions we may ask you to skip, because of your previous answers.

I’ve made a mistake? What do I do?

We would still like you to send your completed survey even if you have made a mistake. Please just completely fill in the box for the incorrect answer and then select the correct box.

Can I give the survey to my spouse/friend/someone else to fill in?

You may ask for help in filling in the survey but it should be completed using your own experience, not the experience of your spouse/friend/other. The survey asks about the experiences of the person named on the letter that was sent with the paper version of the survey.

Can I help someone fill in the survey?

Yes, that’s fine. If a friend or a relative needs help in filling in the survey, you can offer help. But the answers should be about their experience only.

I have a complaint about my cancer treatment that’s not covered by the survey. How do I make my complaint?

If you want to make a comment or complain about the service or care provided by your doctor, oncologist or someone else involved in your care, you will need to contact their office or the hospital. If you have a complaint, there is a staff member responsible for the complaints procedure and he/she will try to resolve the matter with you.

Ipsos cannot help you with any comments or complaints you may have about your cancer treatment. Ipsos is only administering the survey on behalf of the Canadian Partnership Against Cancer and [insert provincial cancer agency name].

**The online survey:**

Where can I find my PIN to complete the survey online?

Your unique PIN to access and complete the survey online is printed on several documents that you received in the mail. Your online PIN can be found at the top right corner of the letter that was included in your mailed survey package. Your online PIN can also be found near the top of the third page on the paper survey. If you received a reminder letter to complete the survey, your online PIN is also printed at the top right corner of this letter.

I’ve lost my PIN which I need to complete the survey online. Can I have it again?

Please contact [insert organization name and contact information] for your PIN to complete the survey online.

Otherwise, four weeks after we send the survey to you we will send a reminder letter to everyone who has not yet already filled in the survey. Your PIN will also be printed at the top right corner of the reminder letter.

Can I take a break part way through completing the survey online?

Yes, you can take a break when completing the online survey. When you are completing the survey online, your responses are saved automatically. You can close the browser window containing the survey whenever you like – your responses will be saved. When you’re ready to continue filling in the survey, simply open your web browser and type [www.CancerTransitionSurvey.ca](http://www.CancerTransitionSurvey.ca). Enter your PIN, and you will be returned to where you left off.

Please note: Although your responses save automatically, your survey will not be considered complete until you press the ‘submit’ button at the end of the survey.

The web link doesn’t work. How do I get to the online survey?

To access the online survey, open your web browser and type www.CancerTransitionSurvey.ca. This should take you to a page that asks for your PIN. Your unique PIN to complete the survey online is printed at the top right corner of the letter that accompanied the paper version of the survey and near the top of the third page of the paper survey mailed to you.

I’ve completed the survey online. Do I still have to return the paper consent form?

Thank you for taking part in the survey.

***If you live in Ontario:***Yes,please send us your signed consent form. We won’t be able to look at your responses or use them to improve the experiences of patients and survivors during the transition between cancer care and other sectors of the health care system unless we have your explicit, written consent to do so.

***If you live in Quebec:*** Please send us your signed consent form or provide verbal consent over the phone. We won’t be able to look at your responses or use them to improve the experiences of patients and survivors during the transition between cancer care and other sectors of the health care system unless we have your written or verbal consent to do so.

***If you live in British Columbia, Alberta, Saskatchewan, Manitoba, New Brunswick, Nova Scotia, Prince Edward Island, or Newfoundland and Labrador:***If you have already submitted the survey then there is no need to do anything else.

The paper survey:

Do I put a tick or cross in the box?

You can put either a tick or a cross in one box for the answer that comes closest to your own opinion or experience.

What happens if I have difficulties completing the survey on paper?

You may contact [insert provincial cancer agency name and contact information] for help. Also, patients who prefer not to complete the survey on paper can complete the survey online via the link on www.CancerTransitionSurvey.ca. Please note however, that only one survey per patient can be accepted.

I’ve lost my survey*/*consent form. Can you send me another copy?

We will send a reminder letter about the survey (and consent form, if applicable) to everyone who has not filled in the survey. This will happen about 4 weeks after the survey was first sent to you.

Do I need to send the cover letter back?

No, you only need to either complete and submit the survey online or mail in the paper version of the survey in the postage paid envelope provided.

When do I need to send it back by?

Please return your completed survey as soon as you can before August 19th, 2016

I have not received an envelope/survey with my letter?

Our apologies if this has happened. If you are unable to access or complete the survey online (PIN provided on letter, survey, and reminder), please contact [insert provincial cancer agency name and contact information] to request another paper survey.

I’ve filled in the paper survey and sent it back. Do I still need to send in the consent form?

Thank you for taking part.

***If you live in Ontario:***Yes,please send us your signed consent form. We won’t be able to look at your responses or use them to improve the experiences of patients and survivors during the transition between cancer care and other sectors of the health care system unless we have your explicit, written consent to do so.

***If you live in Quebec:*** Please send us your signed consent form or provide verbal consent over the phone. We won’t be able to look at your responses or use them to improve the experiences of patients and survivors during the transition between cancer care and other sectors of the health care system unless we have your written or verbal consent to do so.

***If you live in British Columbia, Alberta, Saskatchewan, Manitoba, New Brunswick, Nova Scotia, Prince Edward Island, or Newfoundland and Labrador:***If you have already submitted the survey then there is no need to do anything else.

I sent the consent form back in the same envelope as the survey. Will I need to send you another one?

Please do not worry. If you have already completed the survey then there is no need to do anything else.