

LETTER OF INFORMATION / CONSENT FORM

Study Title: A pan-Canadian study of cancer patients' out-of-pocket costs

National Principal Investigator:

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Purpose of the Study

You are invited to take part in this study on out-of-pocket costs and other financial burdens for cancer patients. We (the study team) are hoping to learn about your cancer related expenses since your cancer diagnosis and see how these expenses may affect your family finances. The costs included in this investigation are: medical costs and non-medical costs (such as travel, parking, daycare-) as well as the impact of your illness on you or your caregiver's ability to work. We are also hoping to understand your health insurance purchases and seem if additional insurance purchase would have been helpful in managing these out-of-pocket-costs.

What will happen during the study?

Your participation in this study is voluntary. If you decide not to participate, it will not affect your care in any way. If you agree to participate, you will be asked to complete a survey at 3 different times: shortly after signing the consent form, then at 2 months and again at 4 months after first entering the study. The survey can be done at clinic visits or online. Each survey will take approximately 20- 30 minutes.

The questionnaire will be asking about your out-of-pocket costs, lost income for you and your caregiver, and travel costs. It will also ask you questions on health insurance purchases. Finally, it will also ask you demographic/background information like your age and education.

Are there any risks to doing this study?

The risks involved in participating in this study are minimal. You may feel uncomfortable while reflecting on your finances from completing the questionnaire.

You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. We will describe below the steps we are taking to protect your privacy.

Are there any benefits to doing this study?

Your participation may help other people in the future by helping us learn about the out-of-pocket-cost of cancer patients and sharing this information with policy makers, but it may not personally benefit you.

Confidentiality

You are participating in this study confidentially. I will not use your name or any information that would allow you to be identified. You will be assigned a study ID, which would be protected by a password. No one but me (Principal Investigator), the research coordinator and student investigators will know whether you were in the study unless you choose to tell them.

The information/data you provide will be coded and kept in a locked cabinet where only I and the study team will have access to it. A master log with identifying information will be kept and stored separately from the data. Study data will be kept on a computer will be protected by a password. No information that shows your identity will be allowed to leave this institution. Once the study has been completed, the data will be kept at the McMaster University DeGroote School of Business (Burlington, Ontario) and under my responsibility for a period of 10 years.

After a period of 10 years, study data will be destroyed under my responsibility. Study data recorded on paper will be shredded and if entered in a computer will be erased.

What if I change my mind about being in the study?

Your participation in this study is voluntary. If you decide to be part of the study, you can withdraw any time during the study period and data will be withdrawn from the analysis. If you decide to withdraw, there will be no consequences to you. If you do not want to answer some of the questions you do not have to, but you can still be in the study.

How do I find out what was learned in this study?

You can expect to have this study completed by approximately **January 2019**. If you would like a brief summary of the results, please let me know how you would like it sent to you.

Questions about the Study

If you have questions or need more information about the study itself, please contact me at:

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This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB) and if you have any questions regarding your rights as a research participant you may contact:

Office of the Chair of HiREB
Telephone: (905) 521-2100 ext. 42013

CONSENT

In completing this form, I confirm that:

- I have read the information presented in the information letter about a study being conducted by **Dr. Christopher J. Longo** of McMaster University.
 - I have had the opportunity to ask questions about my involvement in this study and to receive additional details that I have requested.
 - I understand that if I agree to participate in this study, I may withdraw from the study at any time.
 - I can obtain a signed copy of this form.
 - I agree to participate in the study.
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- Check here to confirm that I, (please provide only your **first name**) _____ consent to participating in this study.
 - Check here to receive a PDF version of the consent form to print or to save for your records.
 - Check here to receive a summary of the study's results.
 - Check here to agree to be sent reminders via email or telephone in order to complete the 2nd and 3rd surveys. I understand that I can always choose not to continue and to complete the remaining surveys. (please provide your **email address OR telephone number**) _____

Signature of Participant

Printed Name

Date

Signature of Person
Conducting the Consent
Discussion (if applicable)

Printed Name

Date