

## **PROS** (Patient Reported Outcomes) **PROJECT**



### **Principal Investigator**

Dr. Hsien Seow, PhD  
Professor

### **Co-Investigators**

Dr. Oren Levine, MD  
Dr. Joanne Britto, MD  
Dr. Courtney Coschi, MD  
Dr. Rosalyn Jeurgens, MD  
Dr. Sarah Mah, MD  
Dr. Hira Mian, MD  
Dr. Kara Schnarr, MD  
Dr. Karen Zhang, PhD, C.Psych

### **Study Coordinator**

Dr. Daryl Bainbridge, PhD

### **Sponsor**

Health Canada

This Study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB) #18795.

### **Study Purpose:**

Patient and family perspectives are very important in assessing the quality of health care.

These perspectives are difficult to obtain because patients are often dealing with their illness and do not want to spend time completing surveys.

The purpose of this study is to determine the feasibility of collecting care-related data from patients and their caregiver. Specifically, we are interested in the potential usefulness of these data for assessing the impact of communication training for oncologists.

### ***If I decide to take part, what do I have to do?***

This research study involves completing an on-line survey (about 30 minutes) sometime in the next 3 days. **There are different surveys for patients and caregivers.** Note that only caregivers that accompanied the patient to clinic will be invited to participate in the study (survey).

This survey asks about your understanding of your illness, your impressions of the conversations you had with your oncologist, and your current quality of life.

Your answers are anonymous and confidential. The responses on these surveys are collected independently and are not shared with your oncologist or anyone at the Juravinski Cancer center. Participation is voluntary.

**Upon your survey completion we will arrange for you to receive a \$50 e-gift card.**

### ***How many people are expected to participate in this study (survey)?***

We expect 50 to 100 patients to complete the Patient Survey and 50 to 100 of their caregivers to complete the Caregiver Survey.

### ***How will privacy be safeguarded?***

This survey is anonymous, which means that the researchers do not know who is taking part. No personal identifiers are linked to the survey. As this survey is anonymous, there is a very low potential for privacy breach.

It is possible that representatives of the Hamilton Integrated Research Ethics Board (HiREB), this institution and affiliated sites, and regulatory authorities (e.g. Health Canada) may consult your original research data to check that the information collected for the study is correct and follows proper laws and guidelines.

***How do I consent or decline to participate?***

Completion of the survey is voluntary and will in no way impact 'your' care. You can withdraw / decline to 'participate' in this survey by not submitting your responses.

Your consent to participate in this survey is implied if you complete and submit the survey. By completing the survey, you are confirming that you have read and understood the information in this information form, have had any questions answered, and agree to take part in this study.

It will not be possible to withdraw your responses once you have completed the survey, because the survey is anonymous and the researchers will not know which answers are yours.

***How do I get my \$50 e-gift card for completing the survey?***

Once you have completed the online study survey, you will be forwarded to a separate survey to provide your name, email address, and ID number (indicated on the study postcard), for us to email you the e-gift card. This information will be kept in a password protected excel file on the McMaster University server.

To address possible fraudulence by individuals not invited to complete this survey, you will need to enter this unique ID number (located next to the QR code on the postcard). Patients and caregivers will each have their own unique code. If your identity cannot be verified and/or if it is suspected that you have completed the survey multiple times, or if the researchers suspect that you may have misrepresented yourself in completing the survey, the research team may withhold/not provide the e-gift card in these cases.

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB). The HIREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, Hamilton Integrated Research Ethics Board at 905.521.2100 x 42013.

This study is being supported by Health Canada.

**If you have any further questions, please contact Daryl Bainbridge (coordinator) at [bainbridgd@HHSC.CA](mailto:bainbridgd@HHSC.CA)**