PARTICIPANT INFORMATION SHEET AND CONSENT FORM

Title of Study: Waiting Room Revolution Program Evaluation

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Sponsor: Health Canada

As an enrollee in the Waiting Room Revolution Program you are being invited to participate in a research study to obtain feedback and assess the impact of this program. This research is being conducted by Dr. Hsien Seow at McMaster University.

The Waiting Room Revolution (WRR) is an educational program intended to help patients and families understand what to expect and navigate the resources they need, along the journey of a life-changing diagnosis. The WRR education is being offered across Canada, either in-person or virtually, in collaboration with our partner organizations.

To decide whether you want to be a part of this research study, you should understand what is involved and the potential risks and benefits. This form gives detailed information about the research study. Once you understand the study, you will be asked to indicate this by typing your name in the designated box on the online consent form, if you wish to participate. Please take your time to make your decision.

The investigators on this study have no conflicts of interest.

WHY IS THIS RESEARCH BEING DONE?

Patients and their families often lack knowledge and confidence in navigating a life limiting illness. They may rely on their health care providers to direct the patient's care, share information, or determine which of their needs to address. Not having a sense of control and understanding in ones' illness journal can result in a suboptimal care experience.

We developed a public-oriented program of resources, the Waiting Room Revolution (WRR), to help patients and families understand what to expect along the journey of a life-changing diagnosis. The WRR is intended to help people feel more in control, confident, and prepared throughout their illness journey. This program is based on insights gathered from thousands of patients and families about their understanding of their illness and its progression, as well as their most intimate details and frustrations in facing a life limiting diagnosis.

This research is being done to assess participant satisfaction with the WRR program and the effectiveness of this education in helping seriously ill patients and their families optimize their healthcare experiences and improve their outlook on their circumstance.

WHAT IS THE PURPOSE OF THIS STUDY?

The overall goal of this study is to establish an evidence-driven program and education materials that can be delivered either in person or remotely (virtually) and that "activates" patients (and their families) living with a serious illness towards being more engaged and knowable participants in their care. Through this study, we will conduct a rigorous evaluation of the WRR program to assess the delivery process and measure the effectiveness of this training for impacting self efficacy and the illness experience.

WHAT WILL MY RESPONSIBILITIES BE IF I TAKE PART IN THE STUDY?

Participation in this research is not required to participate in the WRR education program. To participate in the research, you need to provide informed consent and complete an online survey. We will ask you to complete another survey immediately following the WRR workshop, and another survey 6 months later. The surveys will take 20 to 25 mins each to complete.

The on-line surveys will ask you about your knowledge, skills, and confidence in managing your health and healthcare, your general hopefulness and your quality of life, as well as your satisfaction with the WRR workshop format (after you attended it).

HOW WILL CONFIDENTIALITY OF THE SURVEY DATA I PROVIDE BE ENSURED?

We will collect your name and email address from the survey form (stored on a secure McMaster University server) to link pre and post WRR survey responses, for notifying you to complete the study surveys and to email you your gift cards.

Your responses to questionnaires will be collected in McMaster University Limesurvey. The risk of privacy breach for data collected is minimal but cannot be completely eliminated. Some survey questions have open text response options and information you choose to share may be identifiable, so please bear this in mind. Any identifiable information shared will removed when we analyze the data. As indicated, you may choose not to answer any question.

While the Hamilton Integrated Research Ethics Board (HiREB) has approved using the platform to collect data for this study, there is a small risk of a privacy breach for data collected on external servers. Please talk to the study coordinator or investigator if you have any concerns.

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.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

There are no medical risks to you from participating in this study. Taking part in this study may make you feel uncomfortable in answering questions related to serious illness. You may refuse to answer questions on the questionnaires that make you feel uncomfortable.

If you choose to take part in this study, you will be told about any new information which might affect your willingness to continue to participate in this research.

HOW MANY PEOPLE WILL BE IN THIS STUDY?

It is expected that approximately 500 people will participate in this education program and research across Canada.

HOW DO I GET MY $25 E-GIFT CARD FOR COMPLETING THE SURVEY(S)?

You will receive a $25 e-gift card (Everythingcard, 100+ stores) for completing each of the post WRR survey and the 6-month post WRR survey ($25 per survey). Upon your survey completion we will arrange for you to receive the e-gift card. The online survey will ask for you to provide your name and email address, 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.

WHAT ARE THE POSSIBLE BENEFITS FOR ME AND/OR FOR SOCIETY?

We cannot promise any personal benefits to you from your participation in this program or study. Your participation in this research may help other patients and caregivers by validating the WRR educational resources for future use.

IF I DO NOT WANT TO TAKE PART IN THE STUDY.

The education program and research are voluntary and you can choose not to take part. Choosing not to participate will in no way affect your care or treatment that you are currently receiving. If you no longer wish to participate in this educational program or research please contact the study coordinator, Maggie Civak, civakmr@mcmaster.ca or the study investigator, Dr. Hsien Seow at seowh@mcmaster.ca

WHAT INFORMATION WILL BE KEPT PRIVATE?
Your identifiable data will not be shared with anyone except with your consent or as required by law. All personal information such as your name will be removed from the data and will be replaced with a number. A list linking the number with your name will be kept in a secure place, separate from your file. Your personal information (name and email address) will be deleted once the study is completed. The data, with identifying information removed, will be securely stored electronically on the Principal Investigator's McMaster University Teams account held on a secure server at the university.

If the results of the study are published, your name will not be used and no information that discloses your identity will be released or published without your specific consent to the disclosure.

CAN PARTICIPATION IN THE STUDY END EARLY?
If you volunteer to be in this study, you may withdraw at any time. You have the option of removing your data from the study *OR* information provided up to the point where you withdraw will be kept unless you request that it be removed. You may also refuse to answer any questions you don't want to answer on the surveys and remain in the education program or study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

WILL THERE BE ANY COSTS?
Your participation in this research project will not involve any additional costs to you.

WHAT HAPPENS IF I HAVE A RESEARCH-RELATED INJURY?
There is no expected risk of research-related injury. However, if you indicate agreement with the information in this consent form it does not mean that you waive any legal rights you may have under the law, nor does it mean that you are releasing the investigator(s), institution(s) and/or sponsor(s) from their legal and professional responsibilities.

IF I HAVE ANY QUESTIONS OR PROBLEMS, WHOM CAN I CALL?
If you have any questions about the research now or later, please contact the study coordinator the study coordinator, Maggie Civak, civakmr@mcmaster.ca or the study investigator, Dr. Hsien Seow at seowh@mcmaster.ca

CONSENT STATEMENT

Participant:

By checking the box next to the "informed consent" item on the online survey, I confirm that I have read the preceding information thoroughly. I have had an opportunity to ask questions and all of my questions have been answered to my satisfaction. I agree to participate in this study. I understand that I can download a copy of this form. By agreeing to participate in this study, I do not give up any of my legal rights.

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.