

## **Information about the Reflection Room and Informed Consent for participation in a study associated with installations of the Reflection Room in long-term care homes**

### **Study Title: The Reflection Room® in the time of Covid-19**

**Principal Investigator:** Paul Holyoke, PhD, SE Research Centre, SE Health 416-892-3791  
paulholyoke@sehc.com

**Sponsors/Funders:** The evaluation of the Reflection Room is funded by Saint Elizabeth Foundation, and the Reflection Room materials are funded by Ontario Health Central Region. Family Councils Ontario, Ontario Association of Residents' Council and Centres for Learning, Research and Innovation in Long-Term Care are providing support and guidance for the project.

### INTRODUCTION

If you visit the Reflection Room® in a long-term care home, you are invited to participate in this study because you are a resident, caregiver or staff in a long-term care home. This consent notice provides you with information to help you make an informed choice. Please read this document carefully and ask any questions you may have. All your questions should be answered to your satisfaction before you decide whether to participate in this research study.

If you visit the Reflection Room® in a long-term care home, please take your time in making your decision. You may find it helpful to discuss it with your friends and family.

Taking part in this study is voluntary. You have the option to not participate at all or you may choose to leave the study at any time. Whatever you choose, it will not affect the usual care that you receive if you are a resident, not affect your role if you are a caregiver, and not affect your employment if you are staff.

### IS THERE A CONFLICT OF INTEREST?

There are no conflicts of interest to declare related to this study.

### WHY IS THIS STUDY BEING DONE?

The global Covid-19 pandemic has prompted worldwide experiences of grief, especially in long-term care homes. Many people are trying to find ways to deal with their grief.

Before the pandemic, we set up the Reflection Room® in 62 places across Canada. People were invited to read other people's "reflections" about dying or death, or to write their own. Many people found the



Reflection Room® helpful to come to terms with dying and death, and with talking about it. Many wrote reflections about their grief.

This is an example of a Reflection Room®. We set this up in the Wellington County Museum in Elora, Ontario, in October 2016. You can see the red "Reflection Wall", and the white "Reflection Cards" that are posted on the Reflection Wall.

Now that we are in the time of Covid-19, we think the Reflection Room® might help people working

through their grief. We want to see if the Reflection Room® does do that, and if it does, how we might bring the Reflection Room® to other people.

#### HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

We will be inviting residents, essential caregivers and staff in long-term care homes in Ontario and Alberta to take part in this study. We have no specific target number of people who will take part.

This study should take 6 months to complete and the results should be known in about 9 months.

#### WHAT WILL HAPPEN DURING THIS STUDY?

You are invited to enter the Reflection Room® in a long-term care home and read the reflections of other people about their experiences. If you wish, you can write your own reflection about your experiences or thoughts about what has happened during the Covid-19 pandemic. If you do write something on a Reflection Card, you can pin the Card on the “Reflection Wall”, or you can take the Card away with you.

Alternatively, you are invited to review [thereflectionroom.ca](http://thereflectionroom.ca). and read the reflections of other people about their experiences. If you wish, you can write your own reflection about your experiences or thoughts about what has happened during the Covid-19 pandemic.

If you visit the Reflection Room® in a long-term care home, you will also be invited to answer a short questionnaire asking what you think of the Reflection Room®. The questionnaire should take a few minutes to fill in, but you don't have to answer it if you don't want to.

About a month after the Reflection Room® is in place in a long-term care home, the researchers will collect all the Reflection Cards collected there and the questionnaires. They will analyze the kinds of reflections you and others write, and the answers in all the questionnaires from all the long-term care homes with Reflection Rooms®.

#### HOW LONG WILL PARTICIPANTS BE IN THE STUDY?

You can take as long as you want in the Reflection Room® and you can visit as many times as you want.

#### CAN PARTICIPANTS CHOOSE TO LEAVE THE STUDY?

If you visit the Reflection Room® in a long-term care home, you can choose to end your participation in this research (called withdrawal) at any time that the Reflection Room® is in your long-term care home without having to provide a reason. If you choose to withdraw from the study, you can take any Reflection Card you have written off the Reflection Wall.

Because the questionnaires are anonymous, you would not be able to withdraw your questionnaire, and your questionnaire will be used by the researchers for the purposes of the study.

#### WHAT ARE THE RISKS OR HARMS OF PARTICIPATING IN THIS STUDY?

There are no medical risks to you from participating in this study, but because it is focusing on the experiences you and others have had during the Covid-19, taking part in this study may make you feel uncomfortable.

#### WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?

If you visit the Reflection Room® in a long-term care home, the expected benefit from taking part in this

study is that it may help you or others work through the grief from experiences during the Covid-19 pandemic. We hope the information learned from this study will help other people in the future.

#### HOW WILL PARTICIPANT INFORMATION BE KEPT CONFIDENTIAL?

If you decide to participate in this study in a long-term care home by writing a Reflection Card and putting it on the Reflection Wall, it will be available to be read by others. The research team will collect all the Reflection Cards and analyze them. In addition, all the Reflection Cards will be posted on the online version of the Reflection Room® - [www.TheReflectionRoom.ca](http://www.TheReflectionRoom.ca).

It is up to you to decide what you want to share on your Reflection Card. In Reflection Rooms in the past, most people have not included their names or names of other people on their Cards. You may wish not to put your name or the name of someone else on your Reflection Card, but that is up to you.

If you choose to participate in [thereflectionroom.ca](http://thereflectionroom.ca) by leaving a reflection, it will be posted to [thereflectionroom.ca](http://thereflectionroom.ca).

#### WHAT IS THE COST TO PARTICIPANTS?

No cost.

#### ARE STUDY PARTICIPANTS PAID TO BE IN THIS STUDY?

No.

#### WHAT ARE THE RIGHTS OF PARTICIPANTS IN A RESEARCH STUDY?

If you participate in the Reflection Room® study in a long-term care home, you have the right to be informed of the results of this study once the entire study is complete. We will provide a summary of results to your long-term care home for distribution, and if you would like your own copy, you can contact the research team at [research@sehc.com](mailto:research@sehc.com) and we will send it to you.

If you visit the Reflection Room® in a long-term care home, by entering the Reflection Room® and writing and putting a Reflection Card on the Reflection Wall and/or filling in a questionnaire, you do not give up any of your legal rights against the researcher, sponsors or involved institutions for compensation, nor does this form relieve the researcher, sponsors or their agents of their legal and professional responsibilities.

#### CONSENT

If you write a Reflection Card and post it on the Reflection Wall in a long-term care home or fill in a questionnaire, you will be considered to have agreed to the following statements:

- All of my questions have been answered
- I understand the information within this informed consent notice
- For any Reflection Card I have posted on the Reflection Wall, I allow the research team to collect, analyze and post it on [www.TheReflectionRoom.ca](http://www.TheReflectionRoom.ca)
- I allow the research team to collect and analyze any questionnaire I fill in
- I do not give up any of my legal rights by writing and posting a Reflection Card or filling in a questionnaire
- I agree, or agree to allow the person I am responsible for, to take part in this study.

WHOM DO PARTICIPANTS CONTACT FOR QUESTIONS?

If you have questions about taking part in this study, you can talk to a member of the research team.

That person is:

Paul Holyoke, PhD

Phone: 416-892-3791

If you have questions about your rights as a participant or about ethical issues related to this study, you can talk to someone who is not involved in the study at all. That person is:

Dr. Pravesh Jugnundan, Chair of Southlake Regional Health Centre Research Ethics Board

Phone: (905) 895 – 4521 ext. 6638