

Letter of Information

Supporting the Journey Home: Growing the Community Bundle to Care for those with Serious Illness (SJH)

This program is funded by First Nations & Inuit Home and Community Care – National Branch, Indigenous Services Canada/Government of Canada. The Principal Investigator is Dr. Hsien Seow, from McMaster University. He can be contacted at any time with questions at seowh@mcmaster.ca. This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB). If you have questions about your rights as a participant, please call the Office of the Chair, HIREB, at 905.521.2100 x 42013 or email Dr. Seow.

WHAT IS THE PURPOSE OF THE STUDY?

We want to understand your experience with *Supporting the Journey Home: Growing the Community Bundle to Care for Those with Serious Illness (SJH)*, palliative care education and how it impacts you and your community.

WHY ARE YOU BEING ASKED TO TAKE PART IN THIS STUDY?

We invite all individuals enrolled in the SJH palliative care training. Taking part in this study is voluntary, and whether you choose to participate in the research or not, you will still be able to participate in the palliative care training.

WHAT INFORMATION WILL BE COLLECTED? WHAT IS REQUESTED OF YOU AS A PARTICIPANT?

You will be invited to participate in the following data collection activities, which will take place both before and after the training. You can receive up to \$50 [Everything gift card](#). Participation is expected to take about one hour in total.

1. **Pre-training Survey** – We ask that you take some time before the training to answer this series of questions independently. This will take about 30 minutes, and upon completion, you will receive a \$25 [Everything Card](#) (Choose from 100+ gift card options).
2. **Post-Course Evaluation** – After the training has concluded, you will be invited to independently complete a brief, 7-question survey providing your feedback on the course. This feedback is anonymous. The first five questions ask about how useful, relevant, and understandable you felt the course was, and the last two questions ask about how the course impacted you and what key learnings you will take with you. This will take about 15 minutes.

3. **Post-Training Survey (Four to Six months later)** - Four to Six months after completing the course, you will receive an email with the post-course training survey, which will be similar to the pre-training survey questions. Upon completion of this survey, we will arrange for you to receive a \$25 [Everything Card](#) (Choose from 100+ gift card options).

WHAT ARE YOUR RIGHTS AS A PARTICIPANT?

Your participation in this study is voluntary, and declining to participate in the study will not affect your ability to complete the palliative care training. You can refuse to participate in any part of the study or decline to answer any questions that you do not want to. If you decide to participate, you can also leave the study at any time. You can do so by contacting the investigator listed at the top of this document. If you decide to withdraw from the study, the information that was collected prior to your leaving the study may still be used. That said, no new information will be collected without your permission.

WHAT ARE THE RISKS AND BENEFITS OF PARTICIPATION IN THIS STUDY?

We do not expect that participating in this research will have any negative effects. However, we recognize that since the palliative and end-of-life care training sessions include specific references to death, dying, and grief, reflections and discussion may trigger an emotional reaction. Should you have difficulty and require support processing these emotions, we can offer assistance with providing support services and counselling resources (see the list attached). While there are no direct benefits to participation in this study, your participation contributes to our understanding of the effectiveness of this education process, ensuring that it continues to meet the needs of Indigenous health and social care providers. This will ultimately lead to more comprehensive and effective palliative care in First Nations communities.

HOW WILL YOUR INFORMATION BE KEPT CONFIDENTIAL?

The confidentiality of participants will be protected through the safekeeping of data. McMaster University will hold all information obtained during this study. Only the research team will have access to your study data. Data will be kept confidential by de-identifying collected information, meaning that all personal information, such as your name, will be removed from the data and will be replaced with a number. We will keep the data for a minimum of 7 years, after which paper documents will be securely shredded and electronic files erased. For the dissemination of the findings, you will be provided with the option to either use your name or remain confidential by selecting a pseudonym (a made-up name).

WHAT WILL YOUR DATA BE USED FOR:

The results will be communicated to participants and the Indigenous communities involved through a final evaluation report. In addition to informing and improving the education and

delivery process going forward, the findings from this study will also be presented at community and academic conferences and publications so that others may learn from it. No information that discloses the participant's identity will be released or published without specific consent to the disclosure.

WHO CAN YOU CONTACT IF YOU HAVE QUESTIONS ABOUT THE STUDY?

If you have any questions concerning the ongoing research process, please feel free to ask any of the researchers in person at the training. The Principal Investigator, Dr. Hsien Seow, McMaster University, can be contacted at any time with questions at seowh@mcmaster.ca.

WHO CAN YOU CONTACT IF YOU HAVE COMPLAINTS OR CONCERNS ABOUT THE STUDY?

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB). If you have questions about your rights as a participant, please call the Office of the Chair, HIREB, at 905.521.2100 x 42013 or email Dr. Seow.

THIS LETTER IS YOURS TO KEEP FOR FUTURE REFERENCE.

Confirmation of Agreement to Participate

Written Agreement:

By signing this agreement form, I am indicating that I have read the Letter of Information, I understand the risks and benefits to the study, and I agree to participate. By agreeing to participate, I have not waived any rights to legal recourse in the event of research-related harm. My participation is voluntary and I may choose not to answer any question or withdraw from the study at any time. The data will be securely stored at McMaster University for a minimum of 7 years following the completion of the study. I understand I may be contacted by email to receive and respond to the post-survey evaluation 4-6 months after the training and a copy of the research results. All of my questions have been answered.

Do you volunteer to take part in this research study?	Yes ____ No ____
Please indicate the name you would like us to use to refer to you in the dissemination of research findings. You can leave a made-up or fictitious name. Participants can remain confidential and their identity will be anonymized.	

Name (print): _____

Signature: _____ Date: _____

Email address: _____

******Complete the following section ONLY if the participant prefers to provide verbal agreement to participate over written******

Verbal Agreement:

Do you have any questions about the study?	Yes ____ No ____
Do you volunteer to take part in this research study?	Yes ____ No ____
Please indicate the name you would like us to use to refer to you in the dissemination of research findings. You can leave a made-up or fictitious name.	

Statement of Investigator: I have carefully explained to the participant the nature of the above research study and have answered any questions they had. I certify that, to the best of my knowledge, the participant clearly understands the nature of the study and demands, benefits, and risks involved to participants in this study, as well as study protocols for data storage, dissemination, and confidentiality.

Researcher Name: _____

Signature: _____ Date: _____

Participant Name: _____

Email address: _____

Support Services and Counselling Resources

First Nations, Métis and Inuit Hope for Wellness Help Line

Service languages: Ojibway, Cree, Inuktitut, English, French

Provides 24/7 culturally grounded assessment, referrals, support in times of crisis, and suicide intervention.

1-855-242-3310

MMIW Crisis Line

Service languages: English, French

Provides 24/7 support to family, friends and community members who are being impacted by the loss of a missing or murdered Indigenous woman, girl or Two-spirit person.

1-844-413-6649

NWAC Elder Support Line | Canada-Wide

Available Monday-Friday 9AM-11AM EST & 1PM-3PM EST

Call 888-664-7808

Talk 4 Healing

Service languages: Ojibway, Oji-Cree, Cree, English, French

Provides 24/7 culturally sensitive counselling, advice and support to Indigenous women.

1-855-554-4325

Online service at www.talk4healing.com

The Indian Residential School Survivors Society

1-800-721-0066

The National Centre for Truth and Reconciliation - Residential School 24-hour Crisis Line

1-866-925-4419