McMaster University | Institute for Research on Aging

School of Rehabilitation Science

PARTICIPANT INFORMATION SHEET

Title of Study: Pain knowledge and methods for delivering pain education for community-dwelling older adults

Local Principal Investigator, Department/Hospital/Institution:
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WHY ARE YOU BEING ASKED TO BE PART OF THIS RESEARCH STUDY?

You are being invited to participate in a research study conducted by Dr. Luciana G Macedo because you are 65 years or older and in good health and stated you may be interested in participating in our research study. In order to decide whether or not you want to be 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 accept the terms electronically if you wish to participate. Please take your time to make your decision. Feel free to discuss it with your friends and family, or your family physician.

WHY IS THIS RESEARCH BEING DONE?

Pain affects people of all ages, including older adults. Pain among older adults can be associated with frailty, falls, fractures, sleep disturbance, and reduced mobility leading to significantly reduced quality of life. Pain education has been found to improve the individual's understanding of pain mechanisms which can reduce the fear and anxiety associated with pain, change pain perception, as well as encourage and support the use of self-management strategies such as exercise and relaxation techniques. However, there is a scarcity of information on the knowledge and specific needs of older adults to serve as a guide for the development of strategies and resources for pain education programs.

WHAT IS THE PURPOSE OF THIS STUDY?

This study will aim to assess pain knowledge and identify the preferred methods (e.g., booklets, classes, videos) of pain education delivery for older adults living in the community.

WHAT WILL MY RESPONSIBILITIES BE IF I TAKE PART IN THE STUDY?
If you volunteer to participate in this study, we will ask you to do the following things:

- Answer an online survey in the platform LimeSurvey® with a questionnaire to measure your pain knowledge level (Pain Concepts Questionnaire (PCQ)), and questions about your preferences for receiving a pain education program such as in-person *versus* online, short *versus* long videos, with professors *versus* health professionals, and other aspects.
- Answer an online sociodemographic form with information on age, sex (at birth), gender, race, education level, employment status, marital status, and previous experiences with pain (e.g., episodes, chronic or acute, limitation in the activities).
- The length of time to answer the survey will be between 20 to 40 minutes.
- The survey will be completed once.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?
You do not need to answer survey questions that you do not want to answer or that make you feel uncomfortable.

The risk associated with participation in this study is minimal. To minimize the risk of a potential data breach we will store all study data in a McMaster password-protected OneDrive with restricted assess to research staff.

HOW MANY PEOPLE WILL BE IN THIS STUDY?
We will aim to recruit a minimum of 385 people aged 65 years old or older from the community in Canada who read and understand the English language.

WHAT ARE THE POSSIBLE BENEFITS FOR ME AND/OR FOR SOCIETY?
Your participation may help other people with or without pain in the future by receiving pain education content. However, there are no direct medical benefits to taking part in this study.

IF I DO NOT WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?
You need to know that you can choose not to take part in the study. There are no personal harm or consequences if you choose not to participate in this study ~~in not participating in this study~~.

WHAT INFORMATION WILL BE KEPT PRIVATE?
We will only collect your anonymous information in this survey. The study database will be created in a McMaster password-protected OneDrive which only the research staff have access to. At the end of the study, your anonymized data will be kept and will comprise a research resource database.

The researchers, this institution and affiliated sites, and the Hamilton Integrated Research Ethics Board may access your study records to monitor the research and verify the accuracy of study information. By signing this consent form, you authorize such access.

We will keep the study information for 5 years after the publication related to the study. After this time, all data and electronic copies will be permanently destroyed.

CAN PARTICIPATION IN THE STUDY END EARLY?

Whether you decide to take part in this study or not, there will be no impact on your relationship with McMaster University. There will be no penalty or loss of benefits from deciding not to participate in the study or deciding to withdraw. If you volunteer to be in this study, you may withdraw until the end of the survey and you may decide not to submit it. However, once the survey is submitted data can't be withdrawn due to its anonymous nature. You may also refuse to answer any questions you don't want to answer and remain in the study.

WILL I BE PAID TO PARTICIPATE IN THIS STUDY?
You will not be paid to participate in this study. Your participation will be completely voluntary.

WILL THERE BE ANY COSTS?
Your participation in this research project may not involve additional costs to you. You will need a computer or a mobile cellphone/tablet with internet access to participate.

WHAT HAPPENS IF I HAVE A RESEARCH-RELATED INJURY?
We do not expect any research-related injury due to aspects of the research (i.e., survey). You have not waived any legal rights/rights to legal recourse in the event of research-related harm.

HOW DO I FIND OUT WHAT WAS LEARNED IN THIS STUDY?

We expect to have this study completed by approximately one year. If you would like a summary of the results, please keep connect with the Interdisciplinary Movement and Pain Research in Translational Science (IMPRinT) – McMaster University (https://painmovementresearch.healthsci.mcmaster.ca/)."

IF I HAVE ANY QUESTIONS OR PROBLEMS, WHOM CAN I CALL?
If you have any questions about the research now or later, or if you think you have a research-related injury, please contact Dr Luciana G Macedo by telephone: 289-426-0824 or email: macedol@mcmaster.ca.

CONSENT STATEMENT

Participant:
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.

Date: _____

BOX in LimeSurvey: **I agree to participate in this study.**

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.