

Participant Information and Consent Form Care Partner Advisory Group

Title of Study:	In-Touch: Implementation of a person-centred palliative care <u>i</u> ntervention <u>T</u> o improve comfort, q <u>U</u> ality of Life and social engagement of people with advanced dementia in <u>C</u> are <u>H</u> omes
Principal Investigator:	Dr. Sharon Kaasalainen, McMaster University, School of Nursing, Faculty of Health Sciences, Hamilton, Ontario, Canada
Funded by:	Horizon Europe, European Commission & the New Frontiers in Research Fund

You are being invited to participate in an international Care Partner Advisory Group (CPAG), which is being led by Dr. Sharon Kaasalainen at McMaster University, Hamilton, Ontario, Canada. The CPAG will help with planning and evaluating a large research study across 7 countries in Europe (Ireland, United Kingdom, Italy, Poland, Portugal, Netherlands, and the Czech Republic), called the In-Touch study. The In-Touch intervention is a person-centred palliative care intervention for people with advanced dementia who live in long-term care homes, their families/care partners, and staff. You are being invited to be part of the CPAG because you have experience as a care partner (i.e., a family member) who provides or provided care or support for a person with advanced dementia who lives or lived in a long-term care home.

To decide whether you want to be a part of this study, or not, you should understand what you would need to do and the potential risks and benefits of the study. This form gives detailed information about the research study, which will be discussed with you. Once you understand the study, you will be asked to provide your signed consent if you wish to participate. By participating in this study, you do not give up any rights to which you are entitled under the law. Enrollment in another study is allowed when you are part of this study. Please take your time to make your decision.

WHAT IS THE PURPOSE OF THE CARE PARTNER ADVISORY GROUP (CPAG)?

The CPAG will include 2-4 family care partners with lived experience in advanced dementia and palliative care across all partner countries, including the 7 countries involved in testing the In-Touch intervention, Canada, Slovenia, and Belgium. Members of the CPAG will support the research activities during the 5-year project. We are

interested in providing care partners with a chance to voice their opinions and to help with this research, using their experiences. We plan to involve 20-40 family carers, and up to 10 researcher “buddies” (e.g., a research team member from each partner country) to make a group of up to 50 individuals.

WHAT WILL PARTICIPATION IN THE CARE PARTNER ADVISORY GROUP INVOLVE?

If you volunteer to participate in this study, the research coordinator at McMaster University will arrange a time to meet with you by phone or by videoconference (MS Teams), to obtain your consent to participate in the study. The research coordinator will then complete a brief survey and interview with you. This will help the research team to learn more about your background and your experience as a family carer/advisor. During the survey, the research coordinator will ask about your gender, age, race, employment status, and your relationship with the person with dementia who lives/lived in a care home. During the interview, the research coordinator will ask about your experience as a care partner/family advisor, how you see yourself in this role, and how the research team can support your participation in this study. You may refuse to answer any questions that are asked during the survey or the interview.

As a member of the Care Partner Advisory Group, you will be invited to participate in virtual monthly meetings (by MS Teams) with other CPAG members. Each meeting will be audio-recorded. These recordings will be destroyed after the meeting minutes are completed.

During the 5-year study, you will be invited to participate in different activities, such as reviewing and providing input on the In-Touch intervention materials. You will also be invited to provide feedback by completing short telephone interviews, or surveys and tools. Each year, and at the end of your participation, you will also be invited to complete a short survey and/or a recorded interview with the research coordinator at McMaster University to give your opinions on the study activities and to share your experience as a member of the CPAG.

The time requested from CPAG members will range between one to two hours each month.

WHAT ARE THE POSSIBLE BENEFITS?

We cannot promise any personal benefits to you from your participation in this study; however, you may find support through the process of sharing with the group and hearing their experiences.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

We recognize that participants may find the nature of the conversation difficult at times. The research team members will be sensitive to emotional reactions. If you find the conversation too difficult you may leave the group discussion at any time.

While there is a risk of privacy breach, this risk is small.

The time required to participate in this research study may cause some inconvenience to you. We will minimize this risk by taking your availability into account when planning activities and by letting you know in advance when activities and meetings are scheduled.

WHAT INFORMATION WILL BE KEPT PRIVATE?

Your data will not be shared with anyone except with your consent or as required by law. All personal information such as your name, address, email and phone number will be removed from the data and will be replaced with a study number. A list linking your study number with your name will be kept in a secure place in a research office at McMaster University in Canada. The list will be stored separately from the study data. Any data that is collected on paper, including this consent form, will be stored in a locked cabinet, in a locked research office, at McMaster University. Any data that is collected electronically/digitally (e.g., audio-recordings of meetings or interviews) will be stored in password-protected files on a secure, internal cloud storage system at McMaster University. All information you share in an interview or in a survey is confidential. Only members of the research team will have access to the data from the survey(s) that you complete. Only members of the research team and an experienced transcriptionist will have access to digitally recorded interviews and resulting text documents. Any information that identifies you will be removed from the interview text before it is analyzed. The digital copies of interviews will be erased at the end of the study.

This study will use the Microsoft Teams (MS Teams) platform to hold meetings, collect data, or conduct individual interviews with members of the Care Partner Advisory Group. MS Teams is an externally hosted cloud-based service.

A link to MS Teams' privacy policy is available here: <https://learn.microsoft.com/en-us/microsoftteams/teams-privacy>

The Hamilton Integrated Research Ethics Board has approved using the MS Teams platform to collect data for this study. However, there is a small risk of a privacy breach for data collected on external servers. If you are concerned about this, we would be happy to make other arrangements for you to participate, perhaps by telephone. Please talk to the researcher if you have any concerns.

All participants in meetings will be reminded to keep the discussion confidential but the research team cannot guarantee that your information or responses will not be shared by other participants. Participants also agree not to make any of their own recordings of the content of a meeting or data collection session.

The research coordinator at McMaster University will use email to communicate with CPAG members, and to coordinate study activities. This includes sharing the

times/dates and MS Teams information for meetings, coordinating interviews, and other CPAG activities. There are common risks of using email to communicate:

- Emails are not secure in the way a phone call or regular mail would be.
- If someone sees these emails, they may know that you are a participant in this study.
- Emails may be read or saved by your internet or phone provider.
- Copies of an email may continue to exist, even after efforts to delete the email have been made.

For the purposes of ensuring the proper monitoring of the research study, it is possible that representatives of the Hamilton Integrated Research Ethics Board (HiREB), this institution, and affiliated sites may consult your research data to check that the information collected for the study is correct and follows proper laws and guidelines. By participating in this study, you authorize such access.

If the results of the study are published, your name will not be used and no information that identifies you will be released or published without your specific consent to the disclosure. All information that is gathered in this study will be kept confidential.

You will not be identified in any published results of the study. All information that you give will be stored at McMaster University for up to ten (10) years, after which it will be securely destroyed.

Only members of the research team will have access to the information.

It is important to understand that even with the protections described in this section, there continues to be the risk of an unintentional release of information. The chance that personal information or study data will accidentally be released or looked at by someone else is small.

CAN I WITHDRAW FROM THE CARE PARTNER ADVISORY GROUP?

Participation in the CPAG is voluntary and you may withdraw at any time. If at any time you choose to withdraw from this study, please contact the research coordinator at McMaster University. You also have the option of removing your data from the study if you choose to leave by contacting the research coordinator at McMaster University. Choosing not to participate in this study will in no way affect the care your relative receives.

You may also choose not to answer any questions you don't want to answer during a meeting, an interview, or a survey, and still stay in the study. During this 5-year research project, you will be given information, in a timely manner, that is relevant to your decision to continue or withdraw your participation.

Study Title: In-Touch: Implementation of a person-centred palliative care iNtervention To imprOve comfort, qUality of Life and social engagement of people with advanced dementia in Care Homes

CONSENT STATEMENT

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 the study. I understand that I will receive a fully signed copy of this form.

Printed Name of Participant

Signature

Date consent was provided

Person obtaining consent:

I have discussed this study in detail with the participant. I believe the participant understands what is involved in this Care Partner Advisory Group.

Name of person conducting the consent discussion

Role in Study

Signature Date

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 or welfare as a research participant, in this study please call the Office of the Chair, Hamilton Integrated Research Ethics Board at (905) 521-2100 x 42013.

Should you have any questions about this study, please feel free to contact Dr. Sharon Kaasalainen (McMaster University) at (905) 525-9140 extension 22291 or kaasal@mcmaster.ca or the research coordinator (McMaster University) at (905) 525-9140 extension 21626 or chambt@mcmaster.ca