In-Touch

Improving care for people with advanced dementia

Deliverable D8.1
Virtual PPI Toolkit

Document information

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Partner short names

Abbreviations	Details
UCC	University College Cork
ULANC	Lancaster University
CU	Univerzita Karlova
MUNI	Masarykova Univerzita
UNITO	Universita Degli Studi Di Torino
RBMC	Stichting Radboud Universitair Medisch Centrum
MMSTR	McMaster University
QUB	The Queen's University of Belfast
JU	Uniwersytet Jagiellonsk
UCP	Universidade Catolica Portuguesa
UL	Univerza V Ljubljani
CHC	Crowdhelix Limited
EAPC	European Association For Palliative Care

REVISION HISTORY		
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List of Content

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1.0 Introduction

Patient and public involvement (PPI) in research refers to research that is conducted 'with or by' patients and members of the public, instead of 'to, about or for' them (1, 2). PPI in research occurs when patients, care partners (i.e., family or friend caregivers), and members of the public work in partnership with researchers to influence and shape how research is conducted (2). The collaborative relationship between researchers and PPI members (3) ensures that the voices of people who are most affected by the research – their lived experiences, practical insights, priorities and preferences, are incorporated into all phases of the research design, implementation and dissemination (4, 5). Including the lived experiences of PPI members in research makes research more relevant and more equitable and makes the findings of the research – including research in dementia, more meaningful to all who are affected (3). PPI in research requires early planning by researchers and adequate resources, such as time and funding (1). While PPI is increasingly required by funding agencies in countries such as Canada, the US, and the UK (3, 4, 6), there are also challenges to involving PPI members in research, including underrepresentation of groups (based on culture, race, age gender, language, abilities, etc.), gaps in communication, mistrust, and power imbalances (5). In addition, few studies have evaluated the process or impact of PPI in research (1, 3, 4).

This virtual PPI toolkit was developed to support the PPI Strategy in the In-Touch study (Figure 1). This toolkit was created by adapting and augmenting a paper-based toolkit that was designed by the Canadian research team, to implement a consistent and evidence-based PPI strategy in the *mySupport* study (7). The *mySupport* study (https://mysupportstudy.eu/) was an international study that examined the effectiveness of an advance care planning intervention, called the Family Carer Decision Support (FCDS) intervention, in supporting family caregivers of persons with advanced dementia living in long-term care homes, in making complex decisions about end-of-life care (7). The intervention was tested in 12 long-term care homes across six countries: Canada, Czechia, Ireland, Italy, the Netherlands, and the UK. Family caregivers of people with advanced dementia received an educational booklet, called the Comfort Care Booklet, that focused on end-of-life care for people with dementia, and participated in structured conversations with a trained member of the care home staff, during family care conferences. The study found that family caregivers who received the FCDS intervention reported less uncertainty in decision-making and increased satisfaction with care for the person with dementia by care home staff (7).

An international PPI panel, called the Strategic Guiding Council, was convened early in the *mySupport* study to advise the research team on various aspects, including the Comfort Care Booklet. Using their experience as caregivers of people with advanced dementia, either in the past or present, these family advisors also assisted with interpreting the study findings, and provided recommendations related to disseminating study results (8). The work of the Strategic Guiding Council and the perspectives of the *mySupport* study research team have informed the development of this toolkit (9). The international PPI panel for the In-Touch study was named by the PPI group from the Strategic Guiding Council to the Care Partner Advisory Group (CPAG).

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Figure 1. Patient and Public Involvement (PPI) Strategy for the In-Touch study International Care Partner Advisory Group (CPAG)

Activity	March 2024	April 2024	May 2024	June 2024	August-November 2024	December 2024	January-March 2025
PPI Strategy	Launch Recruitment & Orientation			Engagement in Activities			
	Meetings with work package Leads (researchers) to identify potential Care Partners & Research Buddies	Recruitment of Care Partners and Research Buddies (ongoing) Enrolment & Orientation of Care Partners by PPI Coordinator (ongoing)		Launch of CPAG, 1st monthly meeting	Monthly CPAG meetings		Monthly CPAG meetings
Evaluation		▪ Intake Interview with Care Partners ▪ PPI coordinator field notes		▪ Care Partner Participation ▪ Activity Tracking ▪ Minutes from monthly CPAG meetings		▪ Annual Individual Interviews with Care Partners ▪ Feedback from Research Buddies	▪ Care Partner Participation ▪ Activity Tracking ▪ Minutes from monthly CPAG meetings
Knowledge Products that form the Toolkit	▪ Study protocol ▪ Overview of the Care Partner Advisory Group for Lead Researchers ▪ PPI Coordinator E-mail Recruitment Script	▪ Informed Consent Form ▪ Demographic Questionnaire ▪ Intake interview guide ▪ In-Touch Study Summary for Care Partner Advisors ▪ Guidelines for the Care Partner Advisory Group				• Annual Interview Guide	

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1.1 The In-Touch Study

In-Touch is a person-centred, non-pharmacological, palliative care intervention for people with advanced dementia who reside in long-term care homes, their families, and staff. The In-Touch program builds on previous work that was conducted in the *mySupport* study.

The In-Touch program will integrate, adapt, and implement two existing, complementary interventions - Namaste Care (in the moment care) and Family Carer Decision Support (planning for future needs which includes the Comfort Care Booklet), in a cluster randomized controlled trial in 56 care homes across 7 European countries: **Ireland, United Kingdom, Italy, Poland, Portugal, Netherlands, and Czechia.** The intervention has great potential to improve the care of residents who have advanced dementia, including comfort, pain and symptom management; to enhance a proactive palliative care approach among staff; and to foster family-staff partnerships in shared decision-making on 'in the moment care' (Namaste Care) and future care planning (Family Carer Decision Support). In addition, the intervention will promote the socialization of residents and a greater sense of involvement for families in the care process. As such, it has the potential to reduce health inequities by ensuring that residents with dementia access optimal palliative care by integrating health and social sciences along with humanities.

The In-Touch study is supported by nine work packages (WPs) to ensure robust planning, contextualizing, and delivery of the intervention, and will engage a consortium of research partners from ten countries; including those involved in the trial (noted above), Slovenia, Belgium (European Association of Palliative Care) and Canada. McMaster University (Ontario, Canada) is leading WP8: **Care Partner Involvement and Engagement**, to ensure that best PPI approaches are followed in the In-Touch study (i.e., planning, education/training, implementation, and evaluation) to ensure that the intervention and dissemination activities are meaningful to people with advanced dementia and their families; and that the knowledge, tools, and resources from all work packages are generated with the people, for the people.

The Public Involvement Impact Assessment Framework (10) and the Canadian Institutes of Health Research (CIHR) Strategy for Patient Oriented Research (SPOR) Patient Engagement Framework (11) will inform the ongoing implementation of the In-Touch PPI Strategy. The guiding principles of the SPOR Framework (11), which underly the In-Touch PPI Strategy, are briefly described in Table 1. This document outlines the launch of the In-Touch PPI Strategy, and the virtual toolkit developed to support its implementation.

Table 1: Guiding Principles for Patient and Public Involvement

Principle	Description
Inclusiveness	Involving PPI members in research promotes diversity in perspectives and reflects their lived experiences.
Support	Providing support and flexibility to PPI members allows them to contribute to discussions and decisions. This includes creating "safe environments that promote honest interactions, cultural competence, training and education"(11) (p.7), and providing compensation for their involvement.

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Principle	Description
Mutual Respect	Researchers, practitioners and PPI members value each other's expertise and knowledge.
Co-Build	PPI members, researchers and practitioners, "work together from the beginning to identify problems and gaps, set priorities for research and work together to produce and implement solutions" (11)(p. 7)

2.0 Objectives

The main objectives of WP8, Care Partner Involvement and Engagement are to:
1) Establish and coordinate an International Care Partner Advisory Group (CPAG) with the support of national CPAG researcher 'buddies' from each partner country,
2) Provide guidance to all CPAG members and national researcher buddies on how to facilitate, maximize and evaluate care partner involvement and engagement using the previously developed PPI toolkit (i.e., for the mySupport project),
3) Co-adapt and localize the In-Touch PPI toolkit to produce virtual tools (information and training material and family resources) for use in national and diverse populations, and
4) Evaluate the processes of engaging members of the CPAG throughout the project.

3.0 Methodology

To address the objectives of WP8, the research team at McMaster University facilitated the recruitment, organization, and maintenance of an **international Care Partner Advisory Group (CPAG)**. Research leads in each partner country (i.e., country partner leads) have worked to recruit 2-4 key stakeholders with lived experience and expertise in advanced dementia and palliative care, who are able to speak and understand English, to support local PPI implementation of the In-Touch intervention and participate in the international CPAG. Researcher buddies from each partner country also attend monthly CPAG meetings to provide support to Care Partner members, and clarification or translation if needed. The enrolment of care partners is ongoing. To date, the group is comprised of Care Partners and Research Buddies from Ireland, the United Kingdom, Italy, Poland, the Netherlands and Canada (Figure 2). Care partners and research buddies from Portugal and Czechia have yet to be identified. Challenges include identifying a care partner who is comfortable communicating in English and securing local research ethics approval in the partnering country.

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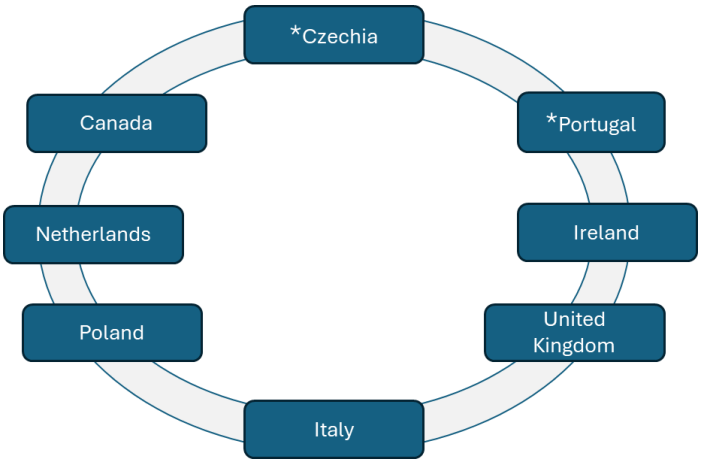
Figure 2. International Care Partner Advisory Group Membership



*care partners and research buddies have yet to be identified

Research ethics approval was obtained by McMaster University (the Hamilton Integrated Research Ethics Board, project 17302) to lead work associated with WP8, house all related data and study materials, complete analysis and publish findings, while working directly with all Care Partner members and their respective national researcher CPAG buddies, across all partner countries. A phased approach has been used to develop study activities, and to obtain required ethical approval.

Figure 3 outlines the steps that were taken and the materials used to launch the In-Touch PPI strategy, including the Care Partner Advisory Group.

Figure 3. Steps taken to Initiate the In-Touch PPI Strategy and Supporting Materials

STEP 1: IDENTIFICATION AND INITIAL CONTACT WITH POTENTIAL CARE PARTNERS AND RESEARCH BUDDIES BY COUNTRY PARTNER LEADS
Overview of Care Partner Advisory Group for Country Partner Lead Researchers
AND RECRUITMENT OF CARE PARTNERS BY PPI COORDINATOR
PPI Coordinator Recruitment Script
STEP 2: CARE PARTNER ENROLMENT
Informed Consent | Demographics Questionnaire | Intake Interview Guide
STEP 3: CARE PARTNER ORIENTATION
One-page Study Summary | Guidelines for Care Partner Advisory Group | Study Overview Presentation
STEP 4: ONGOING CO-CREATION, DATA COLLECTION AND EVALUATION
Monthly CPAG Meetings | Meeting Minutes | PPI Activity Tracking and Evaluation | Annual interview Guide
STEP 5: SHARE STUDY FINDINGS
Guidelines for Co-Authorship and Co-Presentation

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3.1 Step 1: Identification and Recruitment of Care Partners and Research Buddies

Lead researchers in each partner country in the In-Touch consortium met virtually with the Canadian research lead, Dr. Sharon Kaasalainen and the PPI coordinator, and were asked to identify 2-4 care partner volunteers from their various professional networks, and a member of the local research team (e.g., a student or research assistant), to join the CPAG. Care Partner members are, a) individuals who have lived experience as a care partner (i.e., a family member) who provide or provided care or support for a person with advanced dementia in a long-term care home, in the past or present. Care partners of a person with dementia who does not live in long-term care have also been included; b) are 18 years of age or older; c) have a good working knowledge of English (read, speak and comprehend); and d) live in one of the ten partner countries (Ireland, United Kingdom, Italy, Poland, Portugal, Netherlands, Czechia, Slovenia, Belgium, and Canada). Lead researchers received a short summary, describing the plan for the Care Partner Advisory Group.

Upon receiving the contact information of potential Care Partners, the PPI coordinator contacted the care partner by email, using the email recruitment script and arranged to meet with the care partner by MS Teams to explain the study and the CPAG, and review the study consent form. All potential participants received a copy of the study consent form, by email before the consent discussion.

3.1.1 Overview of the Care Partner Advisory Group for Lead Researchers

Seeking Volunteers for the In-Touch Study Care Partner Advisory Group

We are looking for caregiver volunteers to join an international Care Partner Advisory Group (CPAG). This group will advise a team of researchers that is developing and testing the In-Touch intervention in a large 5-year research study across 7 countries in Europe (Ireland, United Kingdom, Italy, Poland, Portugal, Netherlands, and Czechia), called the In-Touch study.

What is the In-Touch Intervention?

The In-Touch intervention is a palliative care intervention for people with advanced dementia who live in long-term care homes, their families/care partners, and staff. The In-Touch intervention has great potential to improve the care of residents who have advanced dementia; to promote a proactive palliative care approach among staff; and to build family-staff partnerships in shared decision-making on 'in the moment care' (Namaste Care) and future care planning (Family Carer Decision Support).

How will the Care Partner Advisory Group be involved?

The research team at McMaster University (in Canada) will hold virtual meetings (over MS Teams) with group members from all partner countries, to gather input and feedback on In-Touch intervention materials and other study activities that emerge as the project progresses. In the *mySupport* study, care partners were involved in activities such as reviewing study recruitment materials, helping with analysis, knowledge translation, and/or presenting and writing publications about the study findings. Essentially care partners can choose activities that they are interested in and feel comfortable contributing to.

Meetings will occur every month and will last from 1-2 hours. We understand that participation may change at times, depending on other commitments. For example, since many care partners will be

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working closely with their local teams to adapt the In-Touch intervention (WP1) in the first year, care partners may not have enough time during this first year to contribute to the international panel. Hopefully, once the work within the adaptations team is complete, time will be freed up to participate more so on the international panel. Care partners can contribute as much or as little as they like.

We are looking to recruit 2-4 care partners and a 'research buddy' per country. The research buddy will be particularly helpful for those countries where English is not their first language.

Please contact us to learn more: PPI Coordinator, McMaster University, Canada Email: XXXXXXX Phone: XXXXXXX

3.1.2 E-mail Script for Recruitment of Care Partners for the international Care Partner Advisory Group

Used by: PPI Coordinator at McMaster University
Target: Potential Care Partner participants for the Care Partner Advisory Group
Purpose: To inform Care partners about the study and set up a time for the consent discussion

Dear (care partner's name),

My name is (name of research coordinator) and I am a research coordinator from McMaster University, in Ontario, Canada. I am contacting you to follow up about participating in a research study. You are being invited to participate in a Care Partner Advisory Group for the In-Touch research study that is taking place at (name of University in country of origin). (Name of research team member) from (name of University in country of origin) let me know that you are interested in learning more about the Care Partner Advisory Group.

You are being invited to participate in the Care Partner Advisory Group (CPAG) because you have experience as a care partner (i.e., a family member) for a person with advanced dementia in a long-term care home, either in the past or present. Members of the CPAG will contribute to planning, implementing, and evaluating the In-Touch intervention, which is being tested in a large research study across 7 countries in Europe (Ireland, United Kingdom, Italy, Poland, Portugal, Netherlands, and Czechia).

The In-Touch intervention is a person-centred palliative care program for people with advanced dementia who live in long-term care homes, their families/care partners, and staff. The In-Touch intervention has great potential to improve the care of residents who have advanced dementia, including pain and symptom management; to enhance a proactive palliative care approach among staff; and to foster family-staff partnerships in shared decision-making.

If you were to participate in this research study as a member of the Care Partner Advisory Group, this is what your involvement would look like:

1. Before our first group meeting: I will arrange to meet with you by phone or by web (MS Teams) to review a consent form that contains more details about the study and the role of the Care Partner Advisory Group, and I will answer your questions. If you give consent to participate, I will also ask you for information about yourself and your experience as a care partner.
2. Regular Meetings: Members of the CPAG will meet virtually, by MS Teams, as a group, to discuss activities of the larger In-Touch project and give feedback as needed. Meetings will occur monthly.
3. Tools and resources: We will also work as a team to adapt resources to ensure that the intervention is meaningful to people with advanced dementia and their families.

We estimate that your time commitment as a member of the CPAG will range between one to two hours each month over the course of this 5-year study. If you choose to participate, please note that your involvement is completely

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voluntary. Declining participation or withdrawing participation will have no impact on you or your relative's care. You can withdraw from the study at any time by contacting us by phone or by email.

All information that is gathered in this study will be kept confidential. You will not be identified in any published results of the study. Only members of the research team will have access to your information.

If you would like to participate, please send me an email (McMaster email address) and let me know when we can meet to review the consent form together, and how you would like to meet (by phone or by MS Teams). I have attached the consent form here for your information.

Thank you for taking the time to read this message! If you have any questions about the study, feel free to contact me here or by telephone at (McMaster telephone number and extension). I hope to hear from you soon.

Attachment: Participant Information and Consent Form – Care Partner Advisory Group

3.2 Step 2: Care Partner Enrolment

To facilitate enrolment, the PPI coordinator at McMaster University obtains informed consent, and collects demographic information, survey and interview data, from all CPAG members directly, to learn about their experiences, and to evaluate PPI processes.

3.2.1 Informed Consent

Care partners from Canada and partnering EU countries provide informed consent to participate in the CPAG (using RedCAP). The PPI coordinator at McMaster obtains informed consent (refer to Participant Information and Consent Form for Care Partner Advisory Group, below) from all care partners before they attend their first CPAG meeting. REDCap is used to obtain digital written consent from participants following the consent discussion with the PPI coordinator at McMaster.

To ensure continued consent throughout the study, members of the CPAG are reminded of their right to withdraw from the study, without penalty, before participating in CPAG activities (e.g., attending meetings or participating in interviews), as well as their right to refuse to answer any question during a meeting, or CPAG activity and still remain in the study.

Participant Information and Consent Form
Care Partner Advisory Group

Title of Study:	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
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

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evaluating a large research study across 7 countries in Europe (Ireland, United Kingdom, Italy, Poland, Portugal, Netherlands, and Czechia), 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 understandwhat 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. Enrolment 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.

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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 isconfidential. 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 ispossible 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.

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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 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.

CONSENT STATEMENT

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

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

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3.2.2 Demographic Questionnaire

After providing informed consent to participate in the study as a Care Partner Advisory Group member, Care Partner members complete a brief demographic survey with the PPI coordinator.

In-Touch Study: Demographic Questionnaire – Care Partner Advisory Group

Study ID: **Date:**

Thank you for agreeing to participate in our study. Please answer the following questions about you. The purpose of collecting this information is so we will be able to describe, as a group, the Care Partner Advisory Group.

1. What is your gender identity? Select one:
   - ❒ Man
   - ❒ Woman
   - ❒ I identify in another way (feel free to describe if you wish):
   - ❒ I prefer not to respond
2. What is your age?
3. What is your relationship to a resident of long-term care?
   - ❒ Spouse
   - ❒ Child
   - ❒ Sibling
   - ❒ Other relative (ex. Niece, nephew, cousin)
   - ❒ Friend
   - ❒ Other (please describe):

4. We believe "race" is a social idea rather than something rooted in biology. Yet, because this idea is widespread, it can affect how people are treated. If you are comfortable doing so, please select the race category (or categories) that describe(s) you. Please check all that apply:

   - ❒ Black (African, Afro-Caribbean)
   - ❒ Indigenous (First Nations, Inuk/Inuit descent, Metis)
   - ❒ Latino (Hispanic descent, Latin American)
   - ❒ Middle Eastern (Arab, Persian, West Asian descent)
   - ❒ South Asian (Bangladeshi, East Indian, Indo-Caribbean, Pakistani, Sri Lankan)
   - ❒ Southeast Asian (Cambodian, Filipino, Indonesian, Malaysian, Thai, Vietnamese)
   - ❒ East Asian (Chinese, Japanese, Korean, Taiwanese)
   - ❒ White (European descent)
   - ❒ Another race category:
   - ❒ Do not know
   - ❒ Prefer not to answer

5. Are you currently employed?
   - ❒ Yes
   - ❒ No
6. If you are currently employed, what do you do for a career? If you are retired/no longer working, what did you do previously in your career?

Thank you for taking the time to answer this survey.

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3.2.3 Intake Interview

After providing informed consent, care partners also undergo a brief (15-30 min.) audio-recorded intake interview with the PPI coordinator at McMaster to learn more about their experience in caring for a person with dementia, their motivation for joining the group, and any previous experience with research. The interview also serves to identify and address any needs or concerns prior to participating in CPAG meetings.

3.2.4 Intake Interview Guide

PPI Coordinator Preamble: *Thank you for agreeing to participate in the Care Partner Advisory Group for the In-Touch Study. We would like to ask a few questions before initiating activities with this group.*
1. What has been your experience working as a family advisor to help guide research? 2. What is your understanding of this role? 3. Why did you choose to participate as an advisor on this project? 4. Do you have any concerns or questions at this point about your involvement? 5. What do you see as the biggest challenge to participating in this group? 6. What do you feel you can contribute to the most? 7. How can we make the experience more pleasant for you? 8. Do you have any concerns about participating that we should know about? a. Timing of meetings b. Language/communication challenges c. Accessing a web-based meeting, e.g., MS Teams, etc. 9. Is there anything important that we haven't discussed that you would like me to know? 10. Do you have any questions? *Thank you for your time.*

3.3 Step 3: Care Partner Orientation

After completing the intake interview, and before the care partner engages in any CPAG activities, including meetings, the PPI coordinator also provides a brief overview of the In-Touch trial, and reviews the role and purpose of the Care Partner Advisory Group in the In-Touch study, using both written and visual materials. Care partners review orientation slides and **Guidelines for the Care Partner Advisory Group** with the PPI coordinator and receive a **1-page study summary**. The Guidelines for the Care Partner Advisory group will be reviewed and revised on an annual basis, with input from all CPAG members.

3.3.1 In-Touch Study Summary for Care Partner Advisors

The In-Touch Study

What is the In-Touch Intervention?

The In-Touch intervention is a non-pharmacological, palliative care intervention for people with advanced dementia who live in long-term care homes, their families/care partners, and staff. The In-Touch intervention has great potential to improve the care of residents who have advanced dementia; to promote a proactive palliative care approach among staff; and to build family-staff partnerships in shared decision-making on 'in the moment care' (Namaste Care) and future care planning (Family Carer Decision Support).

The In-Touch intervention builds on previous work that was conducted in six countries, in the *mySupport* study. The *mySupport* study (https://mysupportstudy.eu/) was an international multidisciplinary study to

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support family carers of persons with advanced dementia living in long-term care homes, in making complex decisions surrounding end of life care (Bavelaar et al., 2022).

The In-Touch intervention will combine two existing, complementary interventions, 1) Namaste Care, 'in the moment care' and 2) Family Carer Decision Support, planning for future needs, which includes a Comfort Care Booklet.

The In-Touch study research team will adapt, implement, and evaluate the In-Touch intervention in a large cluster randomized controlled trial in 56 care homes, in 7 countries: Ireland, United Kingdom, Italy, Poland, Portugal, Netherlands, and Czechia.

How will the Care Partner Advisory Group be involved?

Members of the international Care Partner Advisory Group (CPAG) will use their experience in caring for a person with dementia to provide advice on the In-Touch intervention materials and activities.

The research team at McMaster University (in Ontario, Canada) will hold virtual meetings in English (over MS Teams) with advisory group members from all partner countries, to gather input and feedback on In-Touch intervention materials and study activities that emerge as the project progresses. In the *mySupport study*, for example, care partners were involved in activities such as reviewing study materials/new resources, helping with analysis, knowledge translation, and/or presenting and writing publications about the study findings. Care partners can choose activities that they are interested in and feel comfortable contributing to.

Meetings will occur every month and will last from 1-2 hours. We will identify 2-4 care partners and a 'research buddy' (i.e., a research team member) from each partner country to contribute to the Care Partner Advisory Group.

Questions? Please contact PPI Coordinator, McMaster University, Canada Email: XXXXX Phone: XXXXX

Reference: Bavelaar L, McCann A, Cornally N, et al. Guidance for family about comfort care in dementia: a comparison of an educational booklet adopted in six jurisdictions over a 15-year timespan. *BMC PaliatCare*. 2022; **21**(1): 76. doi:10.1186/s12904-022-00962-z

3.3.2 Guidelines for the Care Partner Advisory Group

In-Touch Study: Guidelines for the International Care Partner Advisory Group
June 2024

These guidelines outline the purpose of the In-Touch study international care partner advisory group (CPAG), and the responsibilities of individual members. They will be reviewed with members at the initial CPAG meeting and thereafter by January 31 of each year.

Purpose

A team of researchers is adapting, implementing and evaluating the In-Touch intervention in a large 5-year research study across 7 countries in Europe (Ireland, United Kingdom, Italy, Poland, Portugal, Netherlands, and Czechia), called the In-Touch study. The In-Touch intervention is a non-pharmacological palliative care intervention for people with advanced dementia who live in long-term care homes, their families/care partners, and staff. McMaster University (Ontario, Canada) is leading the **Care Partner Involvement and Engagement** work of the In-Touch study, including the international Care Partner Advisory Group (CPAG).

Members of the CPAG will use their lived experience and expertise in caring for a person with dementia to provide input on the In-Touch intervention materials and will support study activities throughout the life of the project. The ongoing involvement of CPAG members will help to ensure that the In-Touch intervention and dissemination activities (i.e., how information about the study is shared), are meaningful to people with advanced dementia and their families.

Membership

Members of the international Care Partner Advisory Group will include:

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a) 2-4 care partners from each partner country.
   - Individuals (i.e., family members) who have lived experience providing care or support for a person with advanced dementia in a long-term care home, in the past or present. Care partners of a person with dementia who does not live in long-term care will also be considered.
   - are 18 years of age or older,
   - have a good working knowledge of English (i.e., read, speak and comprehend),
   - live in one of the partner countries (Ireland, United Kingdom, Italy, Poland, Portugal, Netherlands, Czechia, and Canada), and
   - are comfortable communicating by videoconference (MS Teams).

b) A research team member (i.e., research buddy) from each partner country.

c) The research coordinator and a co-facilitator from McMaster University (Ontario, Canada).

Proposed Timeline for the first year (2024)

May-December	Ongoing recruitment and orientation of Care Partners and Research Buddies from partner countries.
August/September	Initial engagement survey
June-December	Monthly meetings of the Care Partner Advisory Group
October/November	Annual engagement interview and survey

Roles and Responsibilities

The roles and responsibilities of each member of the Care Partner Advisory Group will be determined by each individual member. Participation will include:

a) Attending regular monthly Care Partner Advisory Group meetings at an agreed time
b) Reviewing and providing advice and feedback on In-Touch study materials and activities, and
c) Providing advice on strategies used to share study information (knowledge translation and dissemination)

Meetings

a) Monthly meetings will be held by videoconference (MS Teams) and will be 1-2 hours in length.
b) All meetings will be conducted in English.
c) All meetings will be audio-recorded by the research coordinator at McMaster University to capture the group's discussion in meeting minutes. Audio-recordings will be destroyed once the meeting minutes have been approved. CPAG members are reminded not to make their own recordings of any meetings.
d) The research coordinator will take members' availability into consideration when planning all meetings.
e) Meetings will take place between the hours of 9:00 a.m. and 6:00 p.m. for all participants.
f) The research coordinator will circulate videoconference information and meeting materials (e.g., agenda, minutes, and other documents) at least one week prior to a meeting.
g) Meeting minutes will be circulated to all members within two weeks of a meeting and will be approved at the start of each meeting.
h) CPAG members are reminded to keep the group's discussion confidential.
i) CPAG members will let the research coordinator at McMaster know by email if they are unable to attend a meeting. Advance notice (e.g., at least 24 hours before the meeting) is appreciated.

Questions

Please contact PPI Coordinator, McMaster University, Canada Email: XXXX Phone: XXXX

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3.4 Step 4: Ongoing Co-Creation, Data Collection and Evaluation

International CPAG members will meet virtually every month to provide strategic direction and support for PPI activities. The first CPAG meeting was held in June 2024, with the goal that CPAG members will continue to participate over the life of the 5-year In-Touch study (2024-2028). Meeting times were negotiated and decided in advance by all group members. The PPI Coordinator at McMaster serves the coordinator for group meetings, typically facilitates group discussion, and is the primary contact for group members to answer questions outside of meetings or to assist with troubleshooting challenges with technology.

Members of the CPAG use their lived experience and expertise in caring for a person with dementia to review and provide input, advice and feedback on the In-Touch intervention materials and will support study activities, including co-designing, adapting and evaluating virtual tools and e-learning modules to augment the PPI toolkit, as well as activities within other In-Touch work packages. The ongoing involvement of CPAG members will help to ensure that the In-Touch intervention and dissemination activities are meaningful to people with advanced dementia and their families. To evaluate new virtual PPI tools (e.g., video, e-module), CPAG members will be asked to participate in brief interviews (to assess their perceptions of a) user-friendliness; b) content design (e.g., relevance, language, images, videos; c) accessibility (e.g., vision, hearing, physical, cognitive limitations); and d) overall perceptions of the tool), and to complete short surveys and the System Usability Scale (12).

3.4.1 PPI Activity Tracking and Evaluation

Meeting minutes and a tracking sheet are used by the PPI coordinator at McMaster to record and track involvement and engagement activities used in the project for each CPAG member. Meeting minutes are sent by email to all group members following each meeting. Group members appreciate receiving the minutes, as a means of communicating about completed and upcoming activities, and as a useful summary for those who are unable to attend a meeting.

Examples of activities in which the group has been involved to date include, providing input and feedback on an e-learning module related to PPI in Research for Care Partners, the study protocol, and logic model; participating in a discussion on their experiences with shared decision-making which will be developed into a learning resource (video); and contributing to a workshop on PPI in Research for early career researchers.

Throughout the study, CPAG members will also be asked to complete selected modules of the **Public and Patient Engagement Evaluation Tool** (PPEET) (13), to evaluate the quality of their engagement in the study. PPI processes within the project overall (i.e., experiences with the project, and recommendations to support ongoing involvement) will be assessed through individual **annual individual interviews** with each CPAG member.

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3.4.2 Annual Interview Guide

Purpose: Semi-structured interview guide for CPAG members to be completed annually and at the end of the study.

Preamble: *Thank you for agreeing to take part in this interview. Before we begin, I want to remind you that the interview will take no more than 1 hour and will be recorded so that it can be transcribed and analyzed later. Your name and any other identifying information will be removed from the transcript, and only our transcriptionist and I will have access to the audio file. With your permission, I am going to start recording our conversation using a digital recorder.*
During this interview, I will remind you about the activities that the Care Partner Advisory Group has completed for the In-Touch study over the past year. Then, I will ask you some questions to understand your experiences and perceptions as a member of the Care Partner Advisory Group. As you answer these questions, please reflect on your experience [over the last year or over the time that you have been part of the CPAG].

About your involvement:

1. Tell me about your experience as a member of the Care Partner Advisory Group.
   a. What did you like?
   b. What challenges have you experienced as a member of the group?
   c. What would you like to do differently?
2. What was it like to work on activities that informed or impacted the research?
3. Could you tell me about a time when you felt that you were contributing the most, or having the biggest impact as a member of the Care Partner Advisory Group?
   a. What activities were the most meaningful to you?
   b. What activities would you like to do more?
4. What moments have stood out to you from the meetings in this past year?
5. What are the benefits of having a Care Partner Advisory Group as part of the In-Touch study?
6. What impacts do you think the Care Partner Advisory Group has had on the In-Touch study?
7. What other people do you think would be a good addition to the Care Partner Advisory Group?

About the meetings:

In these next questions, I'd like to get your feedback on our meetings.

8. We are interested in your feedback or suggestions about:
   a. the communication that you have received about meetings,
   b. the meeting materials (e.g., agenda, minutes),
   c. study documents that you have received,
   d. the timing and frequency of the meetings - are the meetings too frequent or not frequent enough?
9. What challenges or barriers could make it difficult for someone to participate in the meetings?
10. Is there anything that you would like to change about the meetings or how the group works going forward? What are these changes?
11. How could we better support your involvement in the Care Parter Advisory Group?
12. Do you have any other feedback or comments about the Care Partner Advisory Group that you would like to share?

Thank you for taking part in this interview. We value your perspectives and appreciate the ideas you have shared today.

3.5 Step 5: Share Study Findings

PPI members are subject-matter experts whose lived experience adds value to a research project. Just as PPI members are actively engaged throughout the study, careful consideration will also be given to how best to conclude PPI activities at the end of the study, e.g., by an in-person or virtual meeting to review and acknowledge accomplishments and sharing a one-page summary of study results with PPI members.

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It is important to acknowledge the contributions of PPI members. PPI members' contributions to In-Touch research activities (e.g., videos, educational modules, etc.) will be acknowledged throughout the study.

3.5.1 Authorship and Presentation Guidelines for PPI Members

Co-authorship of scientific papers demonstrates equitable partnership between the researcher and the PPI member (14) and ensures that the perspectives of PPI members are heard (3). Similarly, co-presentation at scientific meetings is a means of recognizing the contributions of PPI members and serves to augment the work with lived experience (3).

Care partner members of the CPAG will be invited to co-author peer-reviewed publications and abstracts, and to co-present at meetings and conferences, based on their level of comfort with co-authorship or acknowledgement. Care Partners will be given the option to be named as co-authors on outputs resulting from CPAG activities, if they are agreeable, and meet the expectations for authorship identified in the target journal.

If care partners do not wish to co-author peer reviewed publications or presentations, they will be given the option to be named in the acknowledgements of the work, or to be acknowledged (privately) as part of the Care Partner Advisory Group.

The following practical advice offered by patient partners (15) will be followed when addressing co-authorship of papers and presentations with CPAG members in the In-Touch study.

- Care Partners will receive an orientation to the publication process.
- CPAG members (researchers and care partner members) will co-create guidelines for co-authorship and acknowledgement in peer-reviewed publications and presentations that outline clear expectations and responsibilities.
- CPAG members will discuss potential peer-reviewed publications and presentations during monthly meetings.
- Care Partners will be given time and flexibility to contribute to peer-reviewed publications and presentations.
- The PPI Coordinator will be flexible in collecting care partners' feedback on peer-review publications and presentations (e.g., by email or virtual meeting).

4.0 PPI Compensation Strategy

Compensation is a means of recognizing the time and expertise of PPI members (6), but should be transparent, equitable (4) and based on the individual needs and circumstances of the PPI member (4, 6). Our goal is to promote a high level of engagement by PPI members across as many partner countries as possible and to provide consistent reimbursement across all Care Partner members.

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Care Partners will be reimbursed, in a timely manner, for all approved travel expenses incurred when participating in Care Partner Advisory Group activities (e.g., meetings, conferences). Travel expenses (e.g., accommodation and transportation) that are reasonable and necessary will be pre-paid where possible or will be reimbursed within 30 days.

- All Care Partner members of the CPAG will receive a small gift ($50) each year, funded through the Canadian partner budget. All compensation will be voluntary and optional.
- Each CPAG member will also have the opportunity to attend one conference (e.g., Namaste Care International, Alzheimer's Europe) over the course of the project, with funding from the Canadian partner budget, as an in-kind payment for their contributions.
- Care Partner members of the CPAG will also have the opportunity to attend annual in-person project meetings. The Canadian partner budget will cover the cost of the Care Partner's airfare, train (if booked ahead of time) and hotel accommodation. The respective country partner budget will cover the cost of other expenses such as meals and incidental expenses, etc., if needed.

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