

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).

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	

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.
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

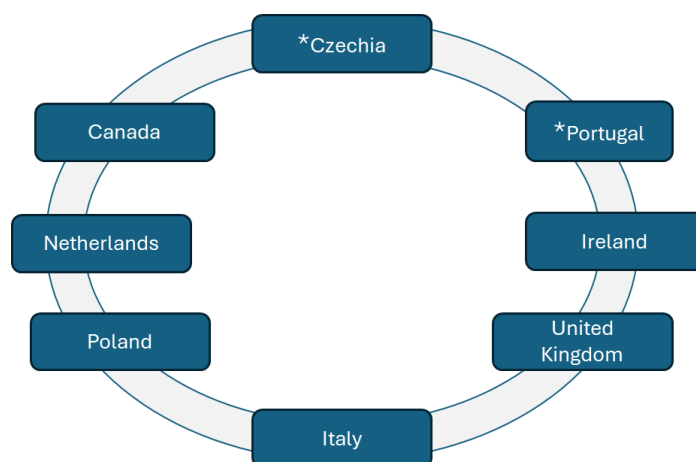
The main objectives of WP8, Care Partner Involvement and Engagement are to:

- 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.

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