



In-Touch: Implementation of a person-centered palliative care intervention to improve comfort, quality of life and social engagement of people with advanced dementia in care homes

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 the 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:

- 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





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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] [Phone]

