

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

Acronym: In-Touch study

Document: 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 the Czech Republic).

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.

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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 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