



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).

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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