



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.

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.

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).



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