



Terms of Reference for the partnership approach – PriCARE Team

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Introduction

To embrace the vision of the Canadian Institutes of Health Research Strategy for Patient Oriented Research - Patient Engagement Framework, the PriCARE study team, including patient partners and academic research team members, was formed to participate in the case management projects. The PriCARE study team values expertise and knowledge of patient partners, which includes, but not limited to, experience living with chronic conditions, navigating the healthcare system, and other skills and experiences acquired in their personal lives. As members of the PriCARE study team, the patient partners and academic research team members meaningfully and actively engage in all aspects of the research, including governance and planning, conducting research, and knowledge translation.

Project background

Individuals with complex health and social care needs often require services from various sectors. This can lead to challenges in receiving integrated care. Case management is a collaborative approach to care which seeks to improve care integration by focusing on meeting individual and family needs including physical, social, emotional, and spiritual aspects, as well as seeking to improve care integration. Case management aims to improve health outcomes for the individual, as well as, the health system as a whole.

Our team has experience implementing and evaluating case management in primary care to better understand how case management works, for whom, and under what circumstances. You can find information on our work on our website: <https://soinsintegres.ca/en/pricare-program-2/>.

Our approach to case management includes an intervention led by a case manager (nurse, social worker, etc.) in collaboration with the healthcare team. This professional works with the individual, as a key member of their care team. They follow-up with the individual regularly, and work with them to coordinate services with other providers. The case management intervention involves four main steps completed in partnership with the patient:

- 1) Assessment of individuals' needs and preferences
- 2) Development and maintenance of a care plan
- 3) Care coordination
- 4) Education and self-management support

Purpose

The Terms of Reference is the guiding document for the PriCARE study team. A first version was co-constructed by the university research team and the patient partners in 2019. The PriCARE study team updated this version in November 2024. The Terms of Reference will be effective until the project end dates or until terminated by agreement from team members.



The team was formed as part of the development of the case management proposal and its subsequent approval by the Canadian Institutes of Health Research (2018). The goals for this team are to collaborate at all stages of the research project. For example, the team members participate in decisions on project priorities, design, and processes; they co-develop research materials; they provide insights and feedback to the overall project; and they contribute to knowledge translation and dissemination.

Team values

PriCARE study team values respect and transparency and embraces diverse opinions. Different perspectives and opinions help shape the team for the better and improve the work of the team. All participants on the team can express themselves freely French or English and are valued equally for their perspectives. PriCARE study team understands that good collaboration takes time and effort to build, and the team is committed to continuously improving collaboration.

Guiding principles

- Research project will respect and include the knowledge, experience, and culture of the team members, which is made up of the university research team and patient partners;
- The role of academic research team members and their professional responsibilities when disseminating the results of their research in academic journals and scientific conferences fulfilled (e.g. submitting publications about research processes and results to academic journals, submitting presentations and posters to scientific conferences, etc.);
- The role of patient partners is recognized and will be valued. Their active and meaningful participation will be encouraged at all stages of the project, and their contribution will be recognized in knowledge transfer products;
- Team members are equal collaborators in all aspects of the research. A process of ongoing consultation and collaboration at all levels will characterize the partnership.

Team members' responsibilities and roles:

All members participate equally in decision making and are valued contributors with individual roles and responsibilities.

Academic research team members are responsible for

- Co-writing protocol for funding;
- Recruiting research participants;
- Providing training to clinicians about the intervention;
- Recruiting, involving, and supporting patient partners.
- Following up with patient partners on compensation and related administrative procedures;
- Providing training and sharing relevant meeting and information documents with team members;
- Defining the internal governance;
- Providing follow-up and feedback on research activities and their progress;
- Answering questions from team members and encouraging regular communication;
- Collecting opinions and suggestions from patient partners to improve the research project;
- Taking initiative and providing leadership on knowledge transfer and dissemination activities;
- Intervening in the event of conflicts or misunderstandings.



Patient partners will help determine what their role in the projects will be, according to their interests. Their role can evolve throughout the course of the projects. Interests may also differ from one patient partner to another. The patient partner role could include activities such as (but not limited to):

- Participating in and leading research meetings and being involved in subcommittees;
- Being actively involved in adapting the intervention;
- Pre-testing clinical and evaluation tools and the development of patient facing materials;
- Assisting with recruitment (e.g., recruitment strategies, preparing recruitment documents etc.);
- Assisting with training of clinical personnel (for example doing mock interview with case managers);
- Creating study materials (e.g. interview guides, questionnaires, observation grids, etc);
- Supporting new patient partners in integrating their role;
- Providing input on the development of academic manuscripts, posters, presentations, etc.;
- Participating in the analysis and interpretation of data;
- Being actively involved in the knowledge translation plan;
- Participate in dissemination activities (e.g: advocating to government on the benefits of case management).

A checklist will be provided to the PriCARE study team members where they check off their areas of strength and interest. The team will review these together once a year.

Supports

It is important that all members of the PriCARE study team are adequately trained in patient partnership, and patient oriented research. This training will be provided to all members of the PriCARE study team.

Some areas of research may be new to members of the PriCARE research team. Training will be provided by the academic research team members in areas of research with which individuals are unfamiliar.

Working Methods

The PriCARE study team will have regular virtual meetings (approximately every 6-8 weeks) to discuss the projects. Meetings will be organized and coordinated by the team. All participants can express their thoughts in French or English. Email, Microsoft Teams, SharePoint, and Google Drive will be used to share documents relating to projects. Notes will be taken as a record of the meeting, capturing agenda items discussed, decisions made, resulting actions, and timelines. The meetings can be recorded to allow new members (or absent members) to have access to the same information.

Patient partners will meet with the academic research team from their home province, as required. The local research coordinator will be their main contact for the studies, and they can reach out to them anytime with questions or for support. They can also access their local support units.

To improve and assess patient engagement throughout the duration of the research project, partnership strategies will be documented. Patient partners may be called upon to share their perspectives, if they so choose, by responding to intermittent survey questions and/or by participating in interviews and/or focus groups.

Patient partners will not be involved directly with the patients participating in the clinical activities of the projects.



Compensation and reimbursement

Patient partners will be compensated for the time they invest in the projects, and the costs associated with their involvement will be reimbursed in agreement with the academic research team in their province. The academic research team must provide patient partners with information about relevant compensation and reimbursement procedures and policies. Accompanied by the academic research team, the patient partners can obtain information from the institutions responsible about the impact that monetary compensation may have on their disability benefits and tax situation.

It is important for patient partners to be fairly compensated, in cash or otherwise, for their time. Academic research team and patient partners must find an agreement that considers the concerns of patient partners as well as the rules and procedures of academic institutions.

Authorship

Academic research team members and patient partners can contribute to study material and academic publications. Their contributions will be recognized with authorship if they agree. They could also be recognized in the acknowledgement section of the publication. If there are several authors, the order of authors will be determined according to the contribution of each. For authors who have contributed equally, authors may be listed in alphabetical order. Academic research team members and patient partners will also have the option to take part in presentations and other research activities. They can accept or choose to step away from these activities as they see fit.

Intellectual property

The material developed for the projects will be registered under a Creative Commons license. Only a limited number of authors will be identified according to the following criteria:

- Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND
- Drafting the work or revising it critically for important intellectual content; AND
- Final approval of the version to be published; AND
- Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Confidentiality

The PriCARE study team must respect the rules of confidentiality as follows:

- Ensure the confidentiality of the information gathered, i.e. not to divulge the identity of participants or any other information that could identify a participant;
- Not to divulge, reproduce, or use the information collected other than for the purposes for which it was communicated;
- Respect the confidentiality of personal health experiences the patient partners share with the team;
- Ensure the physical and computer security of the information collected;
- Ensure that documents containing confidential information are password-protected;
- Obtain the consent of the principal researchers before sharing documents containing confidential information with people outside the PriCARE research team;
- Destroy data collected in a timely manner, as determined by the project's principal researchers;



- Inform the principal researchers of any situation that could compromise the confidentiality of information and the security of research data;
- Respect and protect the principal researchers' intellectual property, i.e. copyrights, patents and brand identity;
- Report any conflicts of interest relating to dual roles and financial interests.

Stepping down

Participating as a member of this study team is voluntary and members are free to step down at any time. Please let a member of the research team know if you would like to step down from your role on the project.

Review

The PriCARE study team will review this terms of reference annually to ensure that the group continues to contribute to the success of the case management projects.

Conflict resolution

If a conflict arises, the PriCARE study team agrees to meet to pursue resolution by negotiation. If the conflict persists despite negotiation between the parties, the PriCARE study team members should agree to identify an external mediator to try to resolve the situation.

List of definitions:

Academic research team: a group of individuals, typically comprised of researchers, research coordinators, research assistants, and graduated students, who collaborate on specific research projects or topics to generate knowledge and advance understanding in a particular field.

Case management: a dynamic and systematic collaborative approach to ensure, coordinate, and integrate care and services for a clientele. An intervention geared towards interdisciplinarity in which a case manager (nurse, social worker or others) evaluates, plans, implements, coordinates, and prioritizes services based on people's need in close collaboration with concerned partners.

Complex health and social care needs: Multiple interactions between physical, mental chronic conditions and/or individual characteristics, such as people's socioeconomic status, culture, and environment.

External facilitators: Experts in research implementation, external to the organization where the implementation is occurring, who assist, mentor, coach, or support individuals, teams and organization to enable adoption of innovations into routine practice in the context of an implementation study.

Patient partner: people with lived expertise, or experience, of a health condition and who agree to contribute their experience and expertise to a research project. They become collaborators with researchers, as an integral part of the research team. In these terms of reference, the term "patient" encompasses anyone who has any experience of the healthcare system. It therefore includes citizens, users of healthcare services, caregivers, advocates, and representatives of affected populations and voluntary health organizations.

Research participant: A person who takes part in a study by completing a questionnaire, responding to a survey, taking part in an interview or participating in a focus group, and whose data are used to answer the research questions.



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