

Integrating Residents as Partners in Long-Term Care (LTC) Research

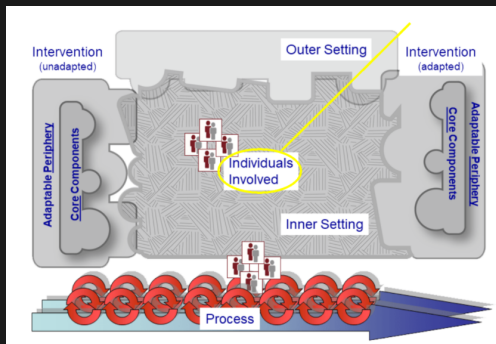
Introduction

The study "COVID-19: Implementation of virtual P.I.E.C.E.S for LTC resident care planning with family to build and sustain team collaboration and workforce resilience" investigated a new, virtual intervention (PIECES) for team-based planning of resident care.

Recent research underlines the importance of family involvement in supporting residents' wellbeing and care planning¹. At our study's inception, two resident partners and two family care partners, from LTC partners X and Y, joined the research team as patient partners. Their feedback and perspectives contributed to aspects of the research design.

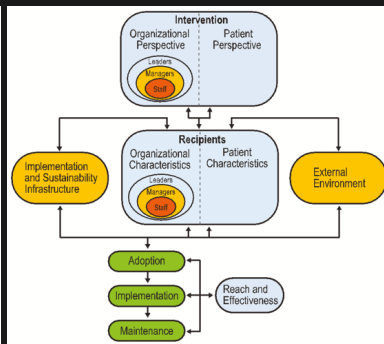
CFIR

The CFIR framework highlights the key characteristics of implementing an intervention (in blue, below).



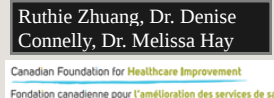
PRISM

The PRISM framework highlights contextual factors that are key to successful implementation of an intervention.



Theoretical constructs of the Consolidated Framework for Implementation Research (CFIR²) and the Practical, Robust Implementation and Sustainability Model (PRISM³) offered a structure to organize findings, as well as a broader lens to understand implementation process and outcomes.

In May 2021, I joined the team and began documenting events in which we had engaged patient partners. Below is our project's Patient-Engagement Timeline, as of August 2021



Tools Used

Two patient-engagement tools were investigated. The Public and Patient Engagement Evaluation Tool (PPEET⁴) and the Patient Engagement In Research Scale (PEIRS⁵) are both questionnaires that evaluate patient-engagement in a research project.

Ex. of questions on each questionnaire:

PPEET

13. I am confident the input provided through this initiative will be used by [organization]

Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree

PEIRS

SU1. I received sufficient support to contribute to the project (for example, orientation, readings, training workshops, webinars)

Strongly Agree Agree Neutral Disagree Strongly Disagree

Lockdown in Ontario

- January 11th**
Patient partner A passes away.
Patient partner B leaves team.
- January 12th**
Patient partners invited to weekly research design meetings.
- January 12th**
Patient partners invited to weekly research design meetings.
- January 13th**
Patient partner B leaves team.
Patient partner C rejoins team.

Gray Zone

- February 16th**
Patient partner D attends research design meeting.

Lockdown in Ontario

- March 23rd**
Patient partners C, D, E and F attend research design meeting.

Ontario Enters Step 2

- May 25th**
Coffee House hosted for patient partners at LTC partners X and Y.
- July 6th**
Patient partners C, D, E and F have their input gathered regarding a scoping review presentation for patient participants at LTC partner X.

Step 3

- July 7th**
Presentation regarding scoping review presented to patient participants at LTC partner X.
- July 20th**
Zoom resources for patient participants and P.I.E.C.E.S "one-pager" presented to patient partners C, D, E and F for feedback.

PR2. The research team members were properly introduced to each other from PEIRS

Strongly Agree Agree Neutral Disagree Strongly Disagree

Events like these can be evaluated using patient-engagement tools, such as PEIRS. Thus, patient-engagement can be formally measured at the end of a research project.

Next Steps

Curiosity about the use of patient-engagement evaluation tools in research led to the start of a scoping review. With the support of my supervisors, I began searching the literature to determine what had been reported regarding the use of patient-engagement tools in LTC research.

Search terms were created and a key articles were obtained. In the coming weeks, we will be searching the following databases; Medline, Embase, CINAHL, Cochrane and Scopus.



Conclusions

From our initial searches, it became clear that there is a lack of a consistent evaluation structure for patient-engagement⁶. Consequently, our ability to "ensure integrity between principles and practices, learn across projects, identify common areas for improvement, and assess the impacts of engagement"⁶ becomes limited.

Thus, it becomes clear that a standardized national framework to measure patient-engagement in research could improve research outcomes and make it easier to assess the benefits of engagement.



Citations

1. Tupper et al., 2020. Family Presence in Long-Term Care During the COVID-19 Pandemic: Call to Action for Policy, Practice, and Research. NCBI.
2. Damschroder et al., 2009. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. BMC.
3. McCreight et al., 2019. Using the Practical, Robust Implementation and Sustainability Model (PRISM) to qualitatively assess multilevel contextual factors to help plan, implement, evaluate, and disseminate health services programs. Oxford Academic.
4. The Public and Patient Engagement Evaluation Tool has been licensed under a Creative Commons Attribution-NonCommercial-Share Alike 4.0 International License. ©2018, Julia Abelson and the PPEET Research-Practice Collaborative, McMaster University. All rights reserved.
a. Hamilton et al., 2021. Shortening and validation of the Patient Engagement In Research Scale (PEIRS) for measuring meaningful patient and family caregiver engagement. PubMed.
5. L'Espérance et al., Developing a Canadian evaluation framework for patient and public engagement in research: study protocol. Springer Link.
- 6.