

RESEARCH DONE IN PARTNERSHIP

Trainee Journal Club

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What is the Trainee Journal Club?

The Trainee Journal Club is an initiative that is helping to build a community that will support aging research done in partnership with people with lived/living experience. Every few months, trainees meet to discuss, ponder, and debate the nuances of conducting research in partnership with older adults.

Meetings are co-facilitated by trainees and use an article of interest to spark discussion amongst trainees. These gatherings provide a platform for trainees to collectively debate and critically reflect on the complexities of research done in partnership with people with lived/living experience.

Meeting Focus

 **Patient and public involvement in international research: Perspectives of a team of researchers from six countries on collaborating with people with lived experiences of dementia and end-of-life**

About the Article

The article examines the role of patient and public involvement in dementia research, specifically focusing on the mySupport study that seeks to implement the family carer decision support intervention for caregivers of individuals with advanced dementia in long-term care homes. Researchers conducted an interpretive description study, which involved 38 interviews with project researchers from six countries (Canada, the Czech Republic, Italy, the Netherlands, Ireland, and the United Kingdom) who were engaged in the mySupport study.

The article outlines these four key themes on researchers' experiences in advancing engagement methods for people with lived experiences of dementia and end-of-life care:

(1) Groundwork to engage in research

(2) Planning for research activities is key

(3) Focus on meaningful engagement

(4) Having foresight for practical issues

What is the mySupport study?

The mySupport study is an international research project focused on the family carer decision support intervention. This intervention is designed to help family carers make informed decisions regarding the care of their loved ones living with advanced dementia as they approach the end of life. The mySupport study aims to adapt, implement, and evaluate an education intervention consisting of two main components: staff training and the provision of a Comfort Care Booklet.

Below is a review of this month's article's four main themes alongside insights from journal club participants' reflections on their learning journeys as researchers.

Theme 1: Groundwork to engage in research

Advocacy for engaging experts by experience

Advocating for the inclusion of people with lived experiences helps demystify the challenges associated with partnering with people with dementia in end-of-life care research.



Consideration for cultural diversities

Recognizing and addressing cultural differences is crucial for inclusive and effective international collaborations.

Partnership with organizations

Collaborating with advocacy organizations supports participant recruitment and enhances research credibility.



Carefully cultivated research team

Assembling a compassionate, well-trained team sensitive to dementia and end-of-life care creates a supportive and constructive research environment.

Insights from journal club participants on establishing a strong foundation for research

Partner recruitment and community engagement

Develop strategies to recruit partners by actively engaging with the community to learn and build meaningful relationships.

Relationship building and clear communication

Establish trust with stakeholders, define clear roles, and use accessible language without oversimplifying the research.

Building team cohesion through introductions

Introduce your partners to all collaborating groups to foster a sense of team spirit and help partners feel more connected to the research.

Tailored involvement and authenticity

Seek input from partners on involvement, compensation, and time commitments, and maintain authenticity to foster successful, meaningful relationships.

Theme 2: Planning for research activities is key

Thoughtful process of engaging people with lived experiences

Partnering with people with dementia can sometimes pose challenges in capturing the experiences of those with advanced prognoses. Engaging caregivers can provide valuable insights but may also lead to burnout, so involving former caregivers is a recommended solution for a more balanced perspective.



Consideration for accessibility and accommodation

Partnerships in research require careful logistical planning to ensure effective collaboration and inclusivity. This includes choosing accessible venues, providing clear, jargon-free materials, and being flexible with scheduling to accommodate participants' availability and needs.

Remunerate for time, knowledge and experience

Timely and fair compensation is essential for recognizing participants' time, knowledge, and contributions. While remuneration fosters mutual respect, ethical dilemmas persist regarding how to equitably compensate different stakeholders, such as caregivers and healthcare professionals.



Insights from journal club participants on planning for research activities

Providing meeting materials in advance

Share materials or one-page updates in plain language before meetings to allow partners to review study progress at their convenience.

Flexible scheduling and participation options

Accommodate partners' schedules by being flexible and consider offering multiple ways for partners to contribute to research.

Advisory group engagement

Partners can provide excellent feedback on data collection methods and may provide valuable insight when piloting interview processes.

Clarify involvement preferences

Ask questions early in the project to identify partners' preferences for involvement and to gauge partners' comfort levels, availability, and time commitment.

Theme 3: Focus on meaningful engagement

Involve with purpose and avoid tokenism:

Researchers emphasized the importance of engaging people with lived experiences meaningfully, not just to meet funding requirements. Research must adapt to include partners' genuine input rather than treating them as procedural additions.

Garnering trust in research relationships:

Building trust through personal connections is crucial, especially in sensitive dementia and end-of-life research. Researchers should avoid medicalized terms like "patient" and focus on clear, accessible communication to foster collaboration.

Strive to create guidance for future research engagements:

Participants of the study highlighted the need to co-design guidelines for effectively involving people with lived experiences in research and knowledge dissemination. They aim to develop international consistency and tools to assess engagement success across countries.



Insights from journal club participants on meaningful engagement

Prioritize purposeful collaboration

Focus on meaningful collaboration with partners by ensuring their involvement has a clear purpose, rather than merely "checking off a box."

Value contributions

Recognize and communicate the significance of partners with lived experience, ensuring they feel valued and respected while actively demonstrating how their input propels the research forward.

Seek partner input

Be aware of any underlying assumptions in your research and actively seek input from your partners.

Theme 4: Having foresight for practical issues



Be mindful of the varied vested interests in partnerships.

Be cognizant of emotional needs and vulnerabilities of partners.

Mitigate challenges of retention and partners' feelings of self-doubt.

Insights from journal club participants on having foresight for practical issues

Foster approachability and open communication
Embrace learning from mistakes

As a researcher, it's essential to be approachable and cultivate relationships that encourage individuals with lived experiences to share their concerns freely.
Recognize that mistakes are a natural part of the research process. Foster a culture of reflection, where team members share lessons learned from challenges.

Key Takeaway

Effective engagement with individuals with lived experiences requires intentional strategies that foster trust, genuine participation, open communication, and adaptability, ensuring meaningful contributions and impactful outcomes.



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This document was collated by Karina Tavernese, with the support of Deedee Begin, Dr. Soo Chan Carusone, & Alison Finney on behalf of the Collaborative's Journal Club participants