

Background

Long COVID and other infection-associated chronic condition communities have been integral in advocating for patient engagement in all stages of research from design and conduct, implementation, through to interpretation, and knowledge translation; nevertheless, the process varies across research teams.

Aims

Our aims were to 1) describe the process undertaking a community-engaged Long COVID research study; 2) evaluate the community-engaged approach, and 3) identify recommendations for community-engaged patient-oriented Long COVID research.

Methods

Project Design: Multi-stage consultation with members of the Long COVID Episodic Disability (LCED) Study team, including persons with lived experiences, researchers, clinicians and staff about their experiences collaborating on the study. Discussions were guided by the 4PI (Principles; Purpose; Presence; Process; Impact) Framework; and Patient-Led Research Scorecards were used to benchmark the quality of patient engagement.

Community Partner Networks and Organizations: The LCED Study involved a community-clinical-academic collaboration involving:

- Patient-Led Research Collaborative (PLRC)
- Long COVID Physio,
- Long Covid Support UK,
- COVID Long Haulers Support Group Canada,
- Long COVID Advocacy Ireland, and Long COVID Ireland.

Guided Discussion using 4PI Framework (January 2024)

- MOH met with LCED Study team members with lived experiences online (Zoom) to discuss the process and impact of patient engagement.
- Community partners were asked to reflect on how they had worked together throughout the study according to the categories of the 4PI.

Patient-Led Research Scorecards (March & April 2024):

- Web-based self-reported questionnaire based on the Patient-Led Research Scorecards administered to all members of the LCED Study team.
- 14 items grouped into 4 domains: 1) Patient Burden; 2) Patient/Partner Governance; 3) Integration into Research Process; and 4) Research Organization Readiness
- Items in each domain were rated from non-collaboration (-2) to ideal collaboration (+2).
- Two additional questions on the usefulness of Scorecards: range from -2 (not useful at all) to +2 (very useful)



Analysis: Descriptive statistics and group-based content analysis of text data.

The Context: Long COVID and Episodic Disability Study

Study Aims

1) To characterize disability experiences among people living with Long COVID in Canada, Ireland, United Kingdom (UK), United States (US); and 2) To develop and assess the measurement properties of a patient-reported outcome measure (PROM) to assess the presence, severity and episodic nature of Long COVID.

Phase 1: Episodic Disability Framework

Study Design: Qualitative descriptive study involving online one-on-one semi-structured interviews with 40 adults living with Long COVID in the four countries. Participants were asked to describe their health challenges living with Long COVID and impact on their overall health.

Phase 2: Episodic Disability Questionnaire

Study Design: Measurement study involving a web-based survey whereby we administered the Episodic Disability Questionnaire (EDQ) to determine its measurement properties to describe the presence, severity and episodic nature of disability among adults living with Long COVID.

Conceptual Foundation

Built from collaborations between KKO and DAB on episodic disability and rehabilitation in the context of HIV (Episodic Disability Framework) Community-engaged participatory research approach



The Project Team

Co-Leads: Researcher + Clinician and Person with Lived Experiences from the full LCED team

Full LCED Study Team: 25 members (12 persons living with Long COVID, 13 researchers, and 5 clinicians (categories are not mutually exclusive).

Core Team: Comprised of co-leads, persons with lived experiences representing community networks, coordinator and clinicians. Co-created and purposefully formed to represent persons with lived experiences and organizations in Canada, Ireland, UK, and US.

Results

Guided Discussion on Community-Engaged Process

Impact

- Composition of the study population was more diverse
- The reality of living with Long COVID was accurately described
- The study outputs were useful and practical
- Influencing and informing the next stage of research

Principles

- No hierarchy
- Sharing of power
- Considerations of fluctuating capacity to contribute to engagement
- Consideration of need to recruit participant with varied demographics and experiences
- Warmth, friendliness and empathy

Strengths


- Establishing clear and simple processes for payment of community partners with honoraria
- Clear communications at a frequency to keep everyone updated but not be burdensome
- Arranging meetings at mutually convenient times
- Providing plenty of notice when work was requested

Areas for Improvement

- Explicitly establishing terms of reference or culture at the foundation of our study; rules of engagement
- Embedding trauma-informed practices at the outset of a project with community partners
- Highlighting the need for more concise and clear email communication
- Further establishing diversity of representation of the patient population on the team



QR code to access the publication of Long COVID Episodic Disability Study Phase 1 Results:



Results

Patient-Led Research Scorecard Results

Domain (Number of Items)	Median Score	
	Researchers (n=5)	Community Partners (n=5)
Scorecard Ratings (Range -2 to +2)		
Patient Burden (4 items)	+1	+2
Patient / Partner Governance (2 items)	+1	+1
Integration into Research Process (5 items)	+2	+2
Research Organization Readiness (3 items)	+1	+2
Utility of Scorecards (Range -2 to +2)		
Usefulness for eliciting perceptions on patient collaboration	+1	+2
Usefulness for fostering collaborative efforts	+1	+2

*4 of 5 responses involved community partners who completed the questionnaire as individuals, 1 response involved group completion of the questionnaire in collaboration with other members of the community network represented.

Recommendations

Recommendations for Use of Scorecards

Guide engagement planning; educating and preparing teams for partnership with people with lived experiences; establishing a common language and understanding patient-engagement; funder can use to evaluate patient-engagement plans for proposed research projects.

Recommendations for Community Engagement

For Researchers	For Community Partners
Establish underlining principles	Clearly communicate updates on study progress
Allow enough time for engagement	Identify your point of contact on the team
Adopt collaborative leadership style	Ask for accommodation when needed
Engage in continuous reflection	Ask for information in a format you can understand
Establish and nurture trust	Share feedback on team process
Engage in fairness of recognition	
Care for community partners	

Conclusions

- Our community-engaged approach enhanced the quality and relevance of the study to community while highlighting areas to enhance meaningful engagement.
- Researchers and community partners broadly agreed as to the quality of community engagement.
- **Strengths:** work was derived from a longstanding international collaboration in HIV, disability, and rehabilitation.
- **Limitations:** team members may have felt reluctant to voice concerns or limitations in the team process.
- Our process and lessons learned will evolve as a team as the study continues over time.

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