Supporting Patient-Provider Collaboration on Long-COVID through Adaptation of Healthlink Model for Building Capacity in Patient Centered Outcomes Research

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Background

- Long COVID is the signs, symptoms, and conditions that continue or develop after initial COVID-19 or SARS-CoV-2 infection

- Known:

15%
report having had long COVID symptoms

6%
report current symptoms

79%
report limitations in daily functioning

- Unknown:
  - Disease pathophysiology and impact
  - Need for standards of care

(WHO, 2022; KFF, 2023)

Healthlink Model

- Establish stakeholder action councils

- Increase stakeholder capacity for research

- Identify stakeholder research priorities and research questions

- Develop partnerships to advance stakeholder research agenda

Project Aims:

1. Adapting the Healthlink model for patient-centered outcomes research (PCOR) on Long COVID in primary-care settings

2. Building PCOR infrastructure and capacity in metro Detroit clinics

Engaging Stakeholders

- Recruit primary care practices affiliated with MetroNet Practice-Based Research Network

- Two groups of patients with Long COVID, providers, and staff from primary care clinics

Advisory & Oversight Committee (AOC)

- **Purpose**: feedback on adapted "Building Your Capacity" curriculum
    - Tailor to new stakeholder group composition
    - Long COVID research focus
    - Research in primary care settings and PBRNs

- **Stakeholder engagement**: 3 patients with Long COVID, 3 providers, and 1 epidemiologist
    - Met monthly for 9 months
    - Virtual 1-hour meetings

Curriculum Modules

Module	Title
Module 1	Introduction to the project and COVID-19 within Detroit
Module 2	Intro to Long-hauler COVID
Module 3	Introduction to PCOR
Module 4	Research Ethics and Institutional Review Boards
Module 5	Engaging in Stakeholder-Driven Research: The Role of Clinicians and the Community
Module 6	Research Protocols in PCOR (Sampling, Recruitment, and Retainment)
Module 7	Developing Research Questions in the PBRN Setting
Module 8	Research Design
Module 9	Qualitative and Quantitative Research Methods
Module 10	Understanding and Sharing Research Findings
Module 11	Obtaining Research Funding and Utilizing PCOR/CER in Health care Improvement and Policy

Primary Care Action Council (P-CAC)

- **Stakeholder engagement**: 5 patients with Long COVID, 4 providers, and 5 office staff
  - Met monthly for 12 months
  - Virtual 2-hour meetings

- **Tasks**:
  - Complete the adapted curriculum
  - Generate/rank priorities
  - Concept mapping and research question generation

Evaluation

- Curriculum evaluation (each module)
  - Engagement: measured through attendance
  - Knowledge gain: measured through knowledge questions after each module
  - Satisfaction: measured through survey after each module

- Partnership process
  - Partnership Process Survey (7 & 12 months)
  - Quantitative Community Engagement Survey (end of project)

Results

Curriculum Outcomes

- Attendance
  - AOC: **71%**
  - P-CAC: **84%**

- Knowledge change
  - Increase in correct answers for most questions (52%)

- Overall satisfaction
  - Very good or excellent for all modules

Curriculum Outcomes

"As a lay person I felt everything was explained so that it could be **understood by all**. There also was plenty of opportunity to ask questions."

"The presentation was easy to follow and understand plus the **example reinforced the information** given before."

General Priorities

Priority	Community Priority Index Score
Information sharing	7.65
Patient-Provider Communication	7.11
Mental Health Impact	6.88
Providers	6.72
Cognitive Impact	6.26

Research Priorities

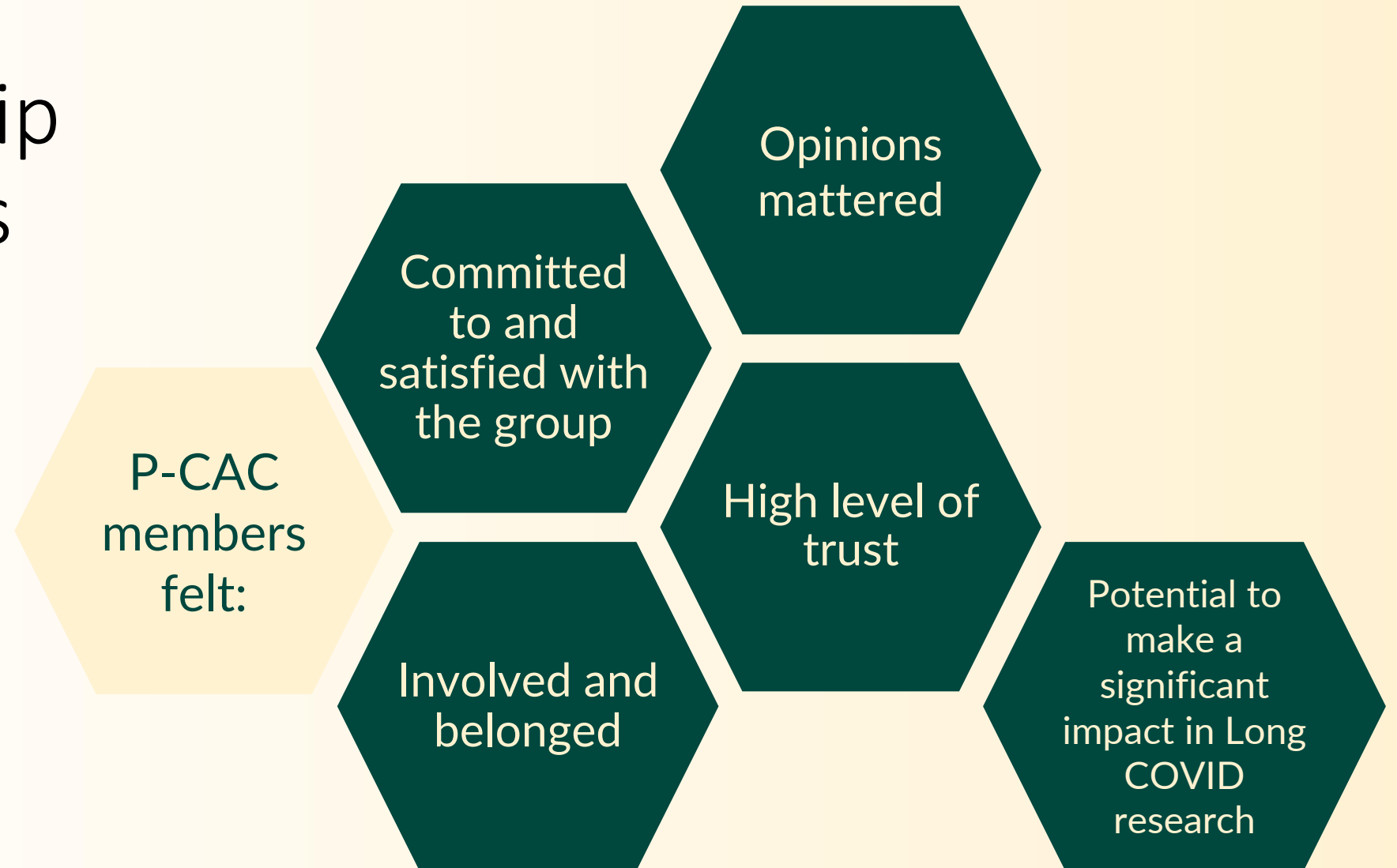| Priority	Score (1 to 3)
Physical Health Impact	2.93
Cognitive Impact	2.8
Mental Health Impact	2.73
Information Sharing	2.67
Providers	2.61

(Salihu et al., 2015)

Cognitive Health Impact of Long-COVID

Research Questions:

- What tools can be developed to help improve cognitive functions?

- What are relations between Long COVID and what we already know from other conditions, and how can we use them to help treat Long COVID patients?

Partnership Outcomes

P-CAC members felt:

- Committed to and satisfied with the group
- Opinions mattered
- High level of trust
- Involved and belonged
- Potential to make a significant impact in Long COVID research
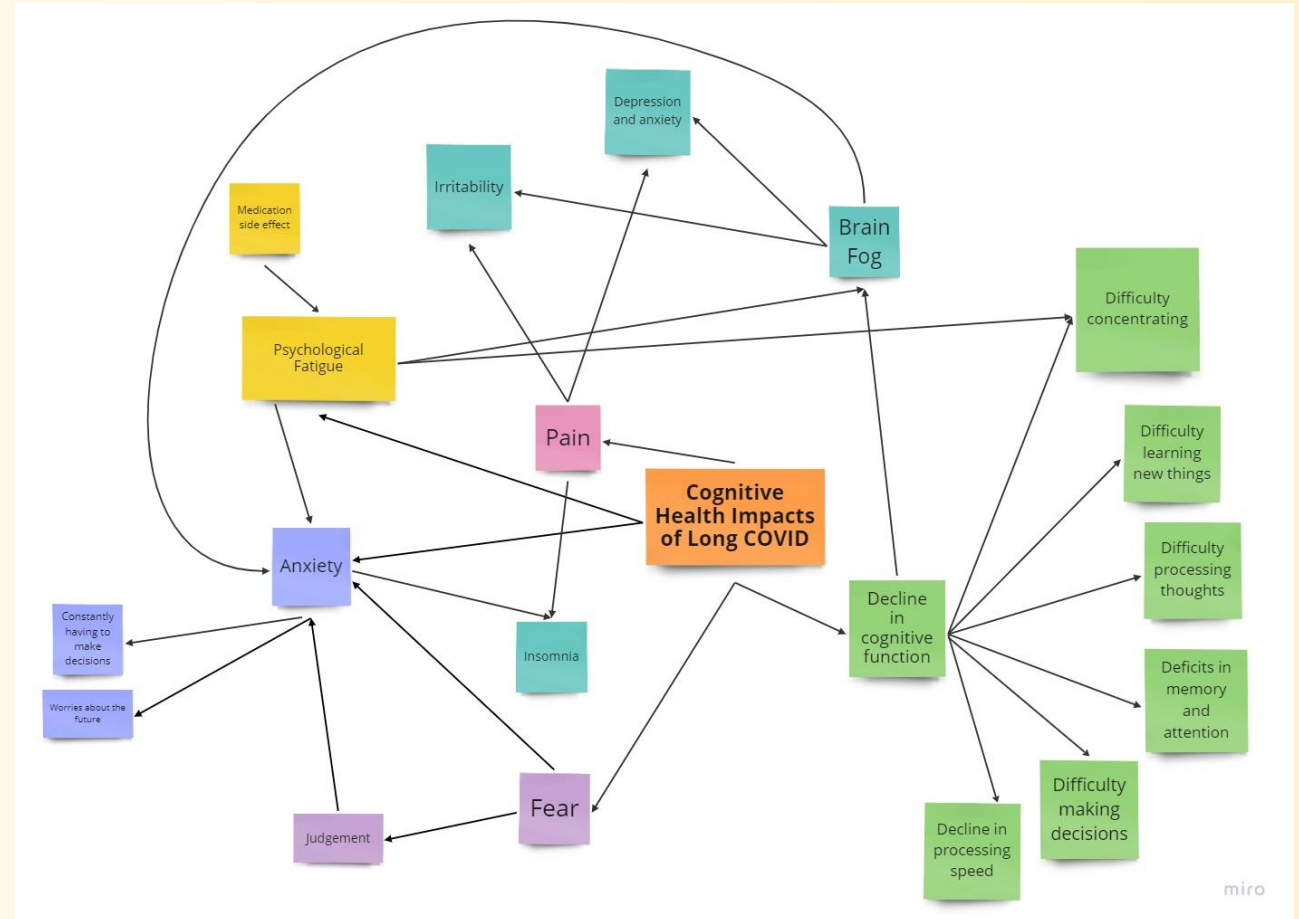
Partnership Outcomes

"It's important that the community has a voice and that I want to continue to help *be a voice for the community*."

"I love being involved in this group gives me *something to look for* each month."

Lessons Learned

- Challenges:
  - Physician reimbursement
  - Time coordination for P-CAC meetings

- Engagement of additional providers

- Balancing curriculum for stakeholder groups with different levels of experience

Conclusions

- Majority of participants found the adapted curriculum engaging and informative

- P-CAC members felt a sense of community, were able to identify shared experiences, and learned from other stakeholder groups

- Benefits of continuous feedback loop

- Future Directions: *Community Education Campaign to Tackle Long COVID* funded by Detroit Medical Center Foundation

Public Health Implications

- Long COVID is prevalent and problematic

- Collaborations between patient and provider groups can provide deep and multifaceted understanding of the disease process and identify shared priorities

- Healthlink is a feasible and acceptable model for continued adaptation

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