

JOURNEY MAP Living with Long COVID

GOAL

To understand the experience of and what matters to patients who are engaged with the Post-COVID-19 Interdisciplinary Clinical Care Network

What Matters

- Validation of LC experience
- Health professional and peer support
- Living and coping well with LC symptoms



1 AWARENESS

- Seek validation in LC support online, through GP, and other medical professionals
- Identify support and request for referral to PCRC



- + Physician referral to PCRC
- Lack of LC awareness among medical professionals → medical gaslighting

What patients feel



Enhance public and medical professionals' awareness of LC and related support in BC

LC = Long COVID

PCRC = Post COVID Recovery Clinic

PCRC

2 ACCESS

- Intake at PCRC with emails, questionnaire, 1-on-1 nurse visits → LC experience acknowledged and validated
- + Access specialized support and relevant research
- Long wait and negative intake experience at PCRC

What patients feel



← Varying degree of LC symptoms to understand & manage →

3 ENGAGE & ONGOING CARE

- Education series led by allied health
- 1:1 appts with allied, nurse and/or physician at PCRC
- Strong peer connections
- Applying self-management tools and skills learned in daily life



- + Developing helpful self-management skills (e.g., pacing, managing energy envelope)
- + Building community
- Challenge in navigating course offering
- Long follow-up questionnaires with unclear clinical utility

What patients feel



4 EXIT

- Discharge from PCRC in various ways
- Self-management without specialized support but with informal peer support
- + Establish informal connections with peers
- + Stay informed via Long COVID Recovery newsletter
- Pressured to leave PCRC with uncertainty

What patients feel



Areas of Opportunity



Enable person-centred intake process



More accessible patient resources and support



Structured and guided self-management course programming



Continued access to PCRC program materials and peer engagement