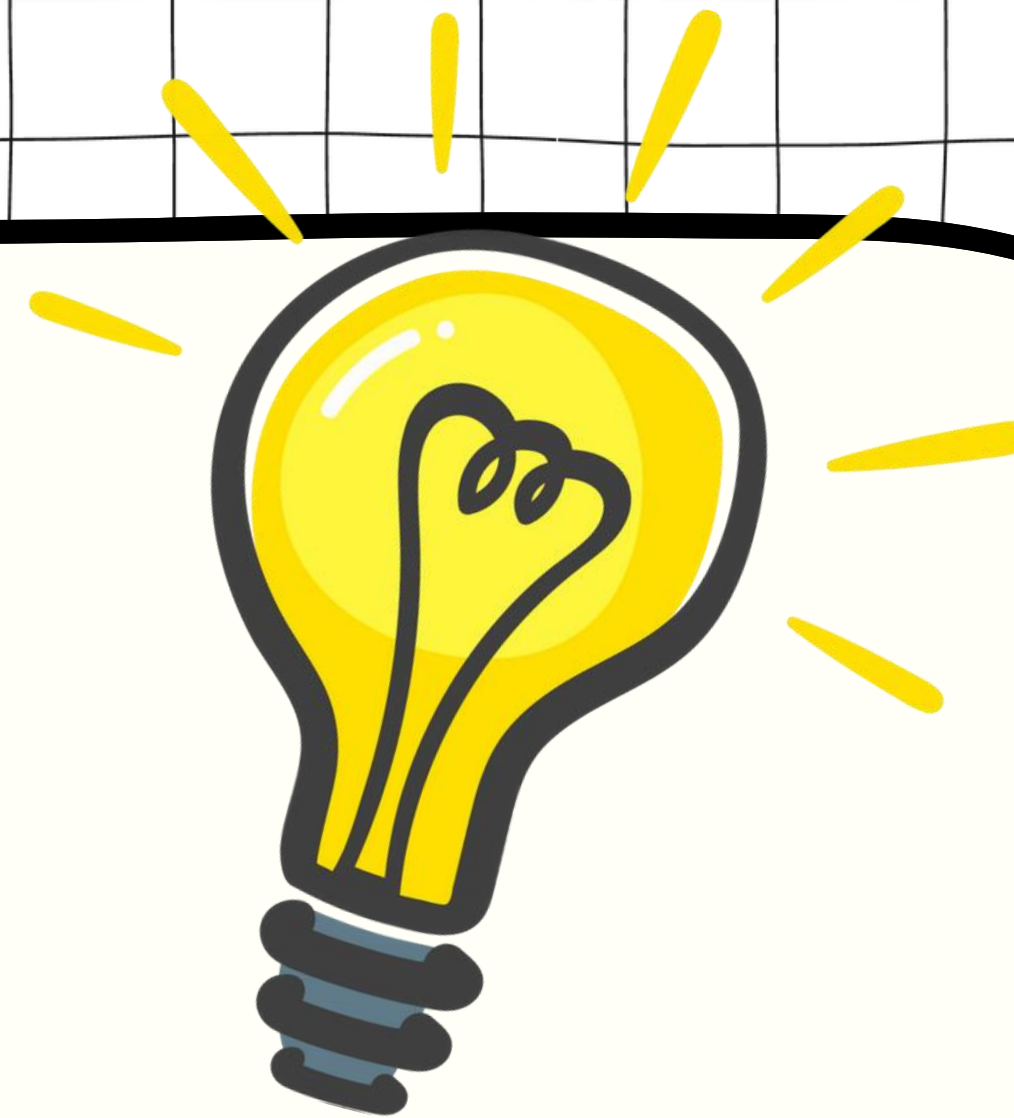


●○○ The 'Long COVID Education and Awareness Hub':

A Public-facing Resource

Jaylyn Leighton, PhD

Postdoc Trainee, St. John's Rehab Research Program



Study Team



**Dr. Marina
Wasilewski**



**Dr. Jaylyn
Leighton**



Logan Reis, MSc

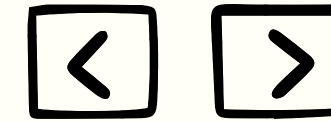


**Abirami
Vijayakumar, MSc**

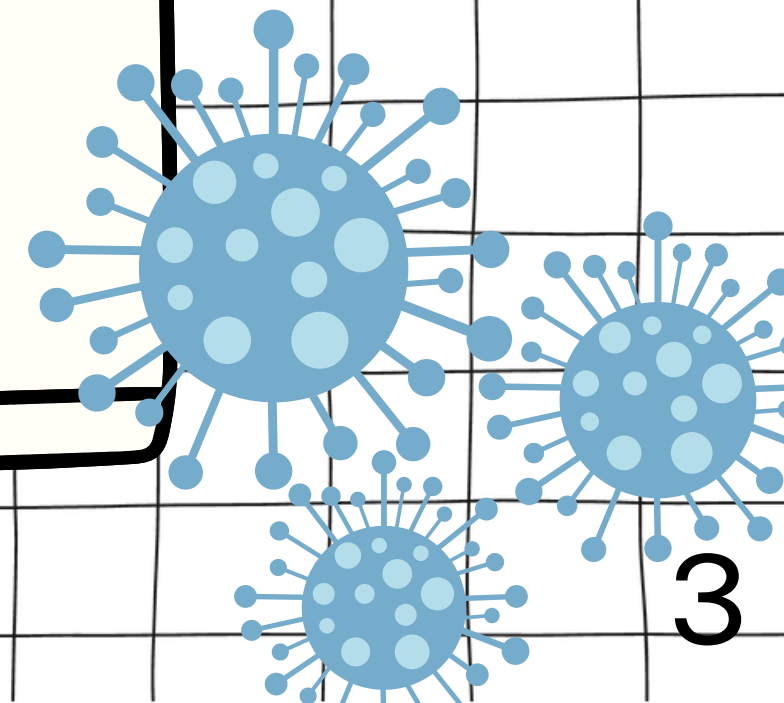


**Dr. Robert
Simpson**

Background Context:



- Between **10–35%** of people who contract the COVID virus will experience long COVID (LC)
- LC is a chronic, episodic condition that affects all **bodily systems** and one's **physical health and cognition** (most commonly, severe fatigue and brain fog)
- LC deeply impacts one's **psychosocial well-being** including activities of daily living, occupational duties, social roles and relationships, and meaningful leisure activities



Objectives of our Project:

To **co-design** an **evidence- and experience-informed 'LC Education and Awareness Hub'** with LC stakeholders (including: people living with LC (PWLC), caregivers (CG), health and social care providers (HSCP), policy-makers, insurance workers, employers, members of the public, etc.) to help **optimize needed rehabilitation and psychosocial supports.**



...

Recap of our research project to date:

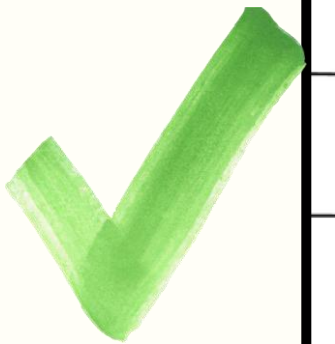
Phase one (April 2022–January, 2023):

1. Quantitative survey (2000+ respondents across Canada)
2. Qualitative interviews: (52 PWLC, 15 CGs, 32 HSCPs)



Phase two (May–July, 2023):

1. LC stakeholder co-design workshops (11 PWLC, 4 CGs, 9 HSCPs)

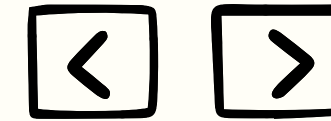


Phase three (current):

1. World Cafe (Oct 27th, 2023)
2. KT projects
3. Pre-implementation workshops



What we learned in phase one related to LC rehab...



From people living with LC and Caregivers:

- PWLC and caregivers experienced challenges **accessing** and **participating in** LC rehab (e.g., lack of knowledge on LC and LC-specific rehab)
- PWLC and caregivers (especially) were put into positions to involuntarily take on **care** and **management** themselves
- PWLC and caregivers identified **needing rehab** to address **physical health** and **psychosocial wellness** (e.g., ADLs, mental health, loss of employment/RTW).



●○○ **“Long COVID’s tough, because it’s so new and medical professionals are figuring it out with us...When you’re from that first wave you didn’t have access to resources... I just feel like we’ve been left to struggle on our own and no one knows how to help us.” - PWLC13**



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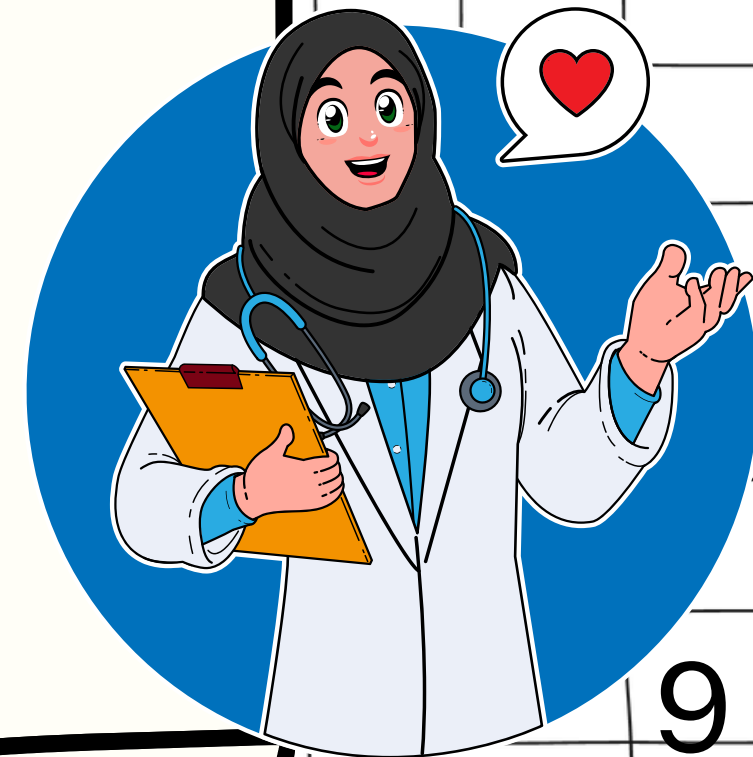
“What you run into as a caregiver is not only did I not sign up for this role but I have no skills or training in this role. I’m doing something that would be very difficult for a professional to do, which is helping someone that’s in incredible distress psychologically.” - CG03



What we learned in phase one related to LC rehab...

From health and social care providers:

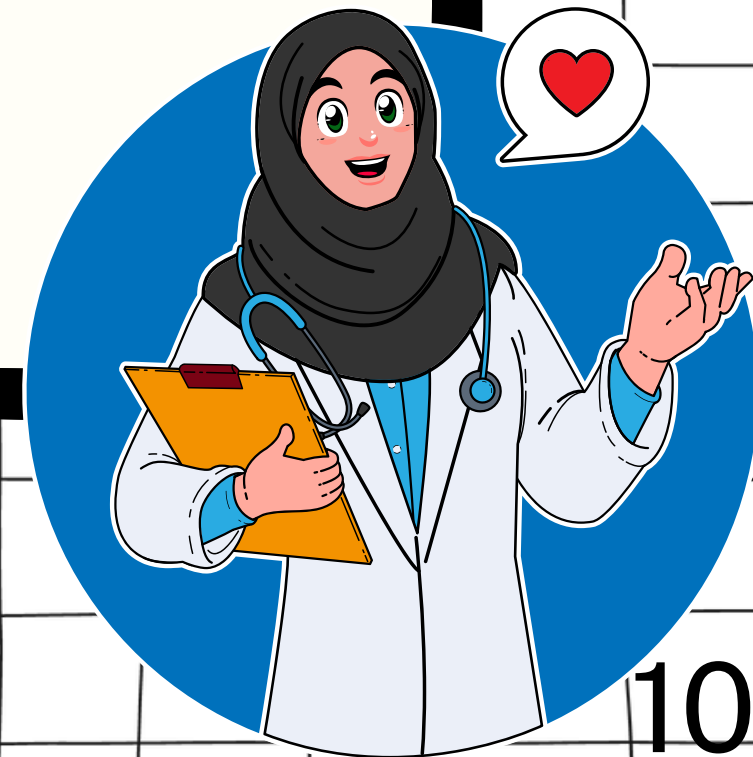
- Lack of adequate resources and supports (e.g., limited LC-specific rehab information)
- Rehab professionals experienced **disruptions in their professional knowledge and experiences** (e.g., re-deployment)
- Rehab professionals were put into positions to **recalibrate their rehab practices** 'on the go' (e.g., adapting rehab practices, expansion of scope of practice)
- Rehab professionals offered recommendations on **best practices**
 - **Affirming** and **validating** rehab practices
 - **Self-management** strategies for at home rehab
 - Group and **peer support** programming
 - Support for informal/family **caregivers**





“We had no answers coming in. We were flying by the seat of our pants with the clinical skills that we had.” -

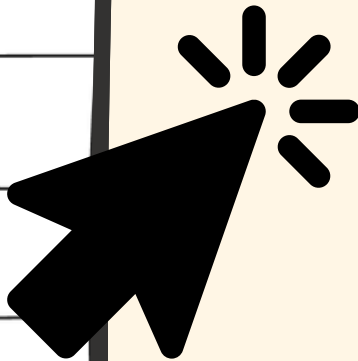
HCP08



Phase III (Current): Knowledge Translation and Pre-implementation

- ○ ○ • **Long COVID World Cafe** (October 27th, 2023)
 - Small group discussions and digital scribing
- **Knowledge translation outcomes**
 - Web design, videographers, digital artists
- **Pre-implementation workshops**
 - Expected: May–June, 2024
- **Launch of the 'hub'**
 - Expected: July, 2024





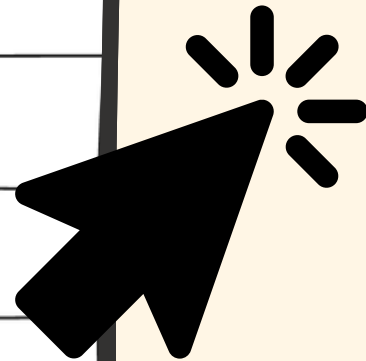
LONG COVID EDUCATION AND AWARENESS HUB

1

EDUCATION



Patient and Family Education Pamphlet and Resource Pages



RESOURCES FOR PEOPLE LIVING WITH LONG COVID

WHAT IS LONG COVID?

- World Health Organization: [Post-COVID-19 condition \(Long COVID\) | who.int](#)
- Government of Canada: [Post-COVID-19 condition \(Long COVID\) - Canada.ca](#)
- Government of Canada: [Initials on COVID-19 science.ca](#)
- Long COVID Web: [Home - LivingWithLongCovid.ca](#)
- Long COVID Physio: [Long COVID Physio: COVID-19: Briefing notes | World Physiotherapy](#)
- Centre for Disease Control: [Long COVID Related Brain Fog, Fatigue, and Mental Health Changes - YouTube](#)
- Patient: [Long COVID: what support is available? | Patient](#)

WHAT SHOULD PEOPLE EXPERIENCING LONG COVID DO?

1. Begin by consulting your family physician, nurse, or nurse practitioner for a proper diagnosis. They can arrange for referrals to the following doctors or rehabilitation professionals as needed:

- A **neurologist** or a **psychiatrist** can provide you with the right medications to help you improve your memory or think clearly once again.
- A **neuropsychologist** or a **cognitive behavioural therapist** can help you find strategies to cope with low mood, heightened anxiety, depression, or sleep changes. You can talk to them about any confusion, memory, attention, or communication challenges. Cognitive therapies and mindfulness strategies might become a helpful part of your daily routine.
- An **occupational therapist** can advise you on strategies to manage your personal level of fatigue, how to avoid what makes it worse, and how to pace yourself to save energy.
- A **physiotherapist** can advise you on what type of exercise or movement would be best for you, and how often to do it, so that you can manage your fatigue levels.
- A **nutritionist** or **dietician** can help you make adjustments to your diet to reduce your fatigue or brain fog.
- A **social worker** can connect you to resources in your community, such as support groups, local community centers with movement or meditation classes, or local practitioners who are skilled in treating fatigue, brain fog, and mental health issues.

For more information: [What Do I Need to Know About Long COVID-related Fatigue, Brain Fog, and Mental Health Changes? - EMC | rhb.gov](#)

WHERE CAN I FIND LONG COVID PEER SUPPORT PROGRAMS?

- Survivor Corps: [Survivor Corps](#)
- Long COVID SOS: [Long Covid SOS Charity | Recognition Research Rehabilitation](#)
- Long COVID Kids: [Long Covid Kids | Charity | Post Covid Syndrome](#)
- COVID Long Haulers Canada: [Covid Long Haulers Canada - COVID Long Haulers Canada](#)

FOR MORE INFORMATION, CONTACT: MARINA.WASILEWSKI@SUNNYBROOK.CA

WHAT ARE THE COMMON SYMPTOMS?

- BRAIN:** Brain fog, memory loss, dizziness, headache, sleep problems, pins and needles, loss of taste or smell, depression, anxiety
- HEART:** Chest pain and tightness, palpitations
- LUNGS:** Breathlessness or shortness of breath, coughing
- ABDOMINAL:** pain, acid reflux, constipation, diarrhea

TIPS FOR MANAGING LONG COVID

- AT HOME:** Gentle movement, be aware of your breathing, invite restful sleep, eat brain-healthy foods, practice patience.
- AT WORK:** Communicate what you are experiencing, avoid overexerting yourself, minimize multitasking, break down work into doable tasks.
- IN SOCIAL SETTINGS:** Talk about your situation, socialize, stay connected in person (as per your comfort) and across distance (e.g., online peer support).
- FOR LOVED ONES:** Start conversations, listen with compassion, take their concerns seriously, identify ways to help, locate resources, advocate.
- FOR EMPLOYERS:** Be flexible and informed, adjust the pace, offer encouragement, believe them.

For more long COVID resources, check out our patient resource page:

and our family/caregiver resource page:

For more information, contact: marina.wasilewski@sunnybrook.ca

Living With Long COVID: Education for Patients, Families & Caregivers

Sunnybrook
ST. JOHN'S REHAB

sunnybrook.ca
Fully affiliated with the University of Toronto
PR 20092 (2024/03/04)



www.LivingWithLongCovid.ca



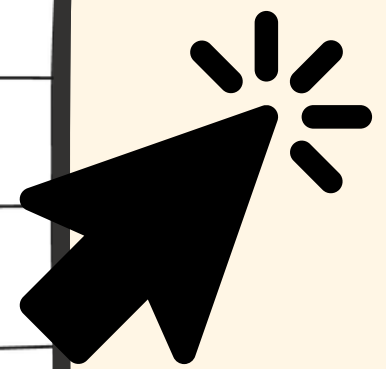
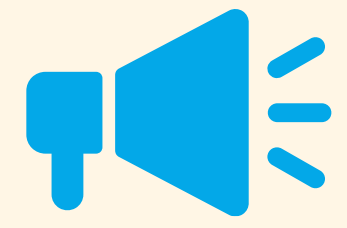
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LONG COVID EDUCATION AND AWARENESS HUB

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ADVOCACY AND PUBLIC HEALTH MESSAGING

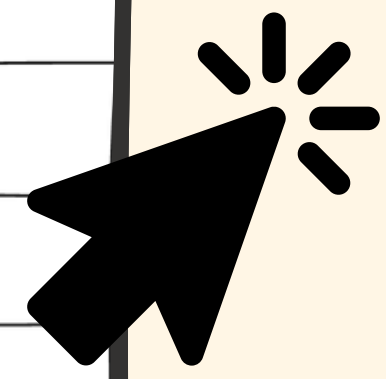


the 'Living with Long COVID' Docu-series: 5-
episodes

Animated whiteboard educational series
(personas and journey maps)

LONG COVID EDUCATION AND AWARENESS HUB

③ HEALTH AND SOCIAL CARE REFORM AND CARE INTEGRATION

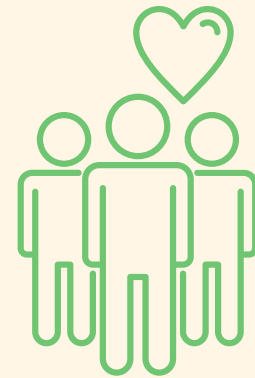


Co-designing a patient navigation model
(LCW grant)*

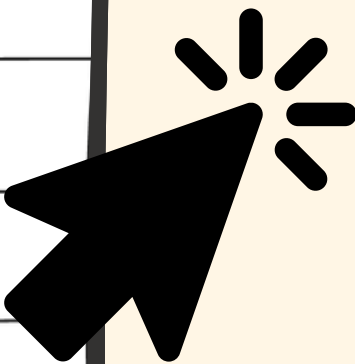
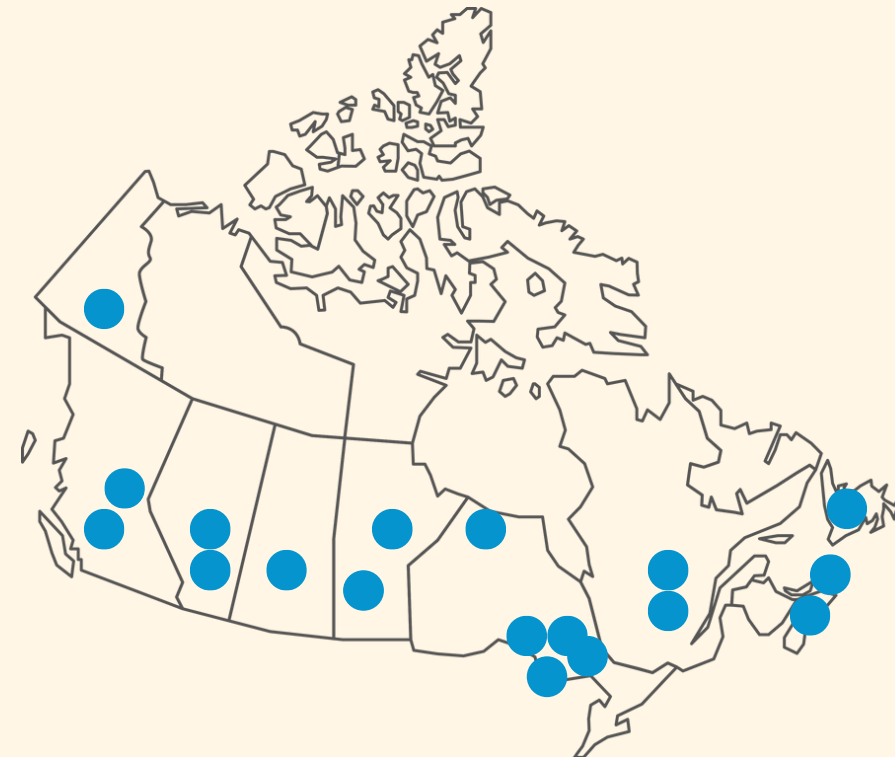
LONG COVID EDUCATION AND AWARENESS HUB

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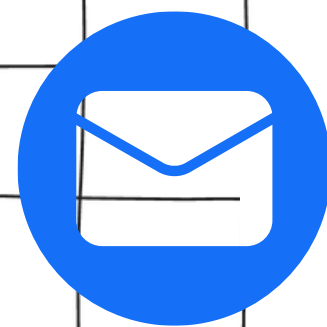
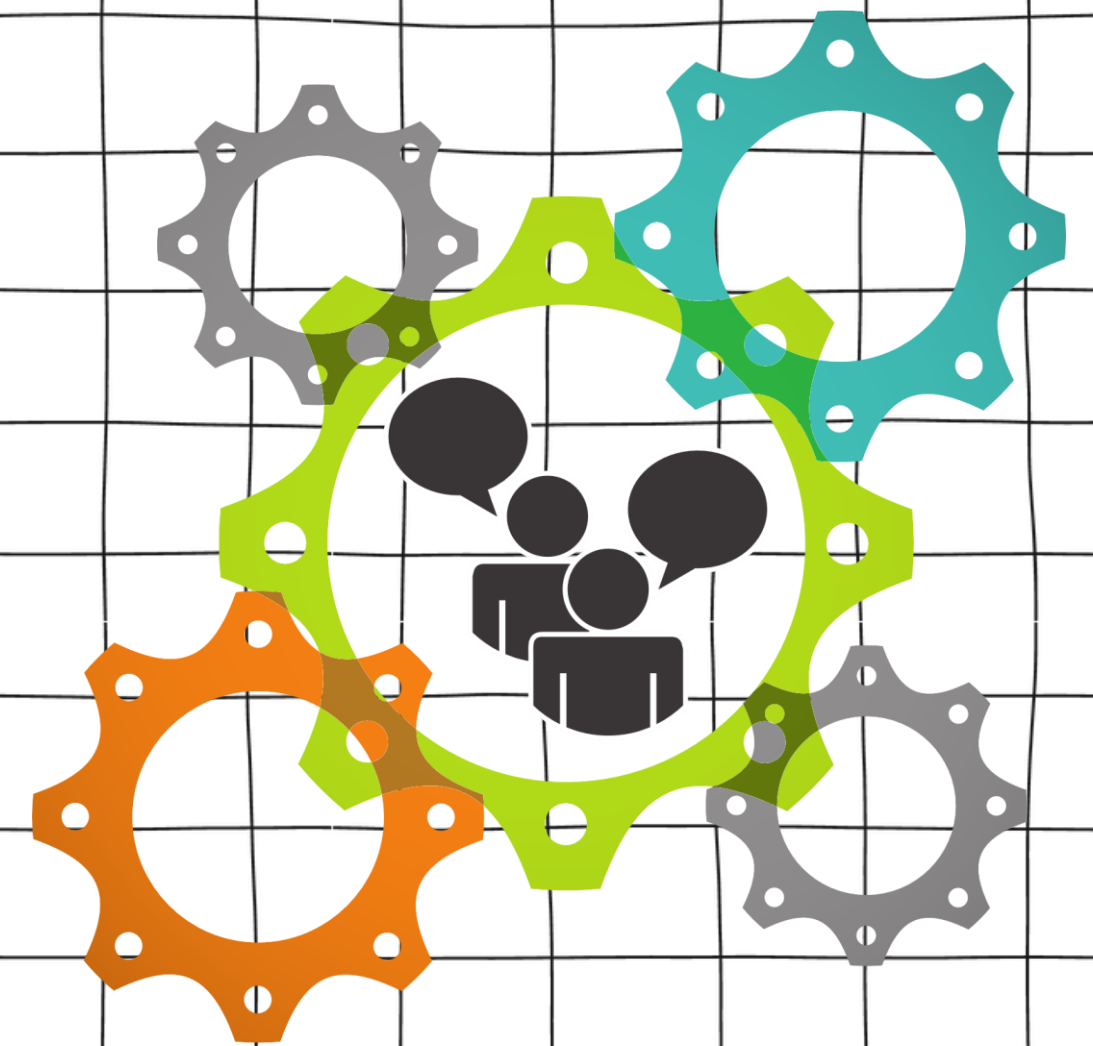
PEER SUPPORT



Environmental scan of active LC peer support spaces



Thank you!



Jaylyn: jaylyn.leighton@sunnybrook.ca