



Interviewees, Understanding the Patient Journey for those living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Fibromyalgia, Symptoms Attributed to Lyme Disease, and Long COVID

Role description

We are seeking 4 patients to participate in a one-time, 1-hour interview to gain a deeper understanding of the patient journey and the diverse experiences of those living with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), fibromyalgia, and symptoms attributed to Lyme disease and long COVID. More specifically, those who are using or have used the Complex Chronic Diseases Program (CCDP) services or the Post COVID Recovery Clinic services in the past year. We hope this information will help inform program planning and further engagement of these populations.

Level of involvement

<u>Consult</u>: We promise to listen, acknowledge, and take your ideas and concerns into consideration as we explore how these programs can be improved. We will then provide feedback on how your input has helped shape and inform program delivery.

Requirements

- Lived or living experience with ME/CFS, fibromyalgia, and symptoms attributed to Lyme disease OR long COVID
- Current or past patients with recent participation since January 2024, in either the CCDP Program or the Post-COVID Recovery Clinic
 - Post-COVID Recovery Clinic: must have attended at least 1 small group session within the past 3-months, and a large group education session
- Comfortable sharing your perspectives and being recorded
- A strong interest in partnering with health professionals and sharing your experiences to help inform our understanding of the patient journey and experience

We hope to recruit diverse voices and welcome patient participants of various ages, genders, and cultural backgrounds from across the province.

Number of positions available

- 2 individuals with lived or living experience of ME/CFS, fibromyalgia, and symptoms attributed to Lyme disease
- 2 individuals with lived or living experience of long-COVID

Commitment

- A one-time, 1-hour interview via Zoom with our interviewer. Breaks available as needed [Prior experience with Zoom is not required].
- Participants will need to have access to the Internet and an electronic device with a camera and microphone (i.e. desktop/ laptop computer, tablet, or cell phone compatible with Zoom)

RSVP questions

Please respond to the following questions by email (saveen.gill@bcrenal.ca) or phone (672-971-0059) by **February 17, 2025**

- 1. Briefly describe your experience with ME/CFS, fibromyalgia, and symptoms attributed to Lyme disease, OR long COVID.
- 2. When did you begin participating in the Complex Chronic Diseases Program or the Post-COVID Recovery Clinic? Are you still currently participating in either of these programs?
- 3. Why are you interested in participating?