

December 15, 2022

RE: Expression of Interest: “Development of a Patient Orientated, Cross –Jurisdictional Long COVID Registry and Community of Practice”

There are many unknowns about Long COVID, including determining such things as the scope and processes of the symptoms, their progression, and how best to manage the disease. One of the key challenges is to characterize Long COVID, such as its prevalence, the range of risk factors, clinical indicators, and health care utilization. With the shared interest in improving knowledge and care around Long COVID, the Provinces are uniting to develop and implement a patient registry—a way to collect information directly from patients, while being mindful of the importance of including the lived experiences of Patient Partners during its development. In addition, the creation of a patient portal will provide patients and the public access to the outcomes from the patient registry so they can directly see the impact it will have on people living with the long-term effects of COVID.

The Long COVID Registry/Community of Practice is recruiting four to six Patient Partners that want to be directly involved in this project. Patient Partner input is being sought for all aspects of the research project and they will play an influential role in shaping these platforms for the betterment of those living with long COVID. We are seeking Patient Partners that are either:

- A patient with past/present lived experience of Long COVID (greater than four weeks of ongoing symptoms)
- A family member or caregiver for someone living with Long COVID

Throughout the timeline of the project, the Patient Partners will be co-designing and collaborating with the research team as they are able through web-based meetings and interactions as well as connections via phone. Collaboration can consist of, but is not limited to the following:

- Proposal writing and grant writing support (4-6 hours)
- Development of meaningful survey questions that directly impacting patients; recommendations on Patient Reported Outcome Measures and Patient Reported Experience Measures (2-4 hours)
- Patient Partner Steering Committee- frequency determined by Patient Partners (up to 8 per year)
- Community of Practice development- design, content, data collection, metrics evaluation (4-6 hours)
- Resource development- resources meaningful to patients and families (4-6 hours)
- Knowledge translation- supporting the way in which the information is used and shared (4-6 hours)
- Patient Partners will also be asked to participate in broader stakeholder engagement/feedback thru 2024

The project will begin as early as January 2023 with target completion of August 2024.

Patient Partners do not need to be experienced with research as they will go through orientation to become a SCPOR Patient Partner, with training provided by Daphne Kemp from the SCPOR patient engagement team. Honoraria will be provided. **Special considerations and support will be in place to accommodate Patient Partners' needs. Submission of interest deadline: January 8th, 2023.**

Please contact Daphne Kemp SCPOR/ SHA Patient Engagement Specialist at daphne.kemp@saskhealthauthority.ca or 306-491-9084 with any questions or to submit your interest.

Thank you

Daphne Kemp RSW