

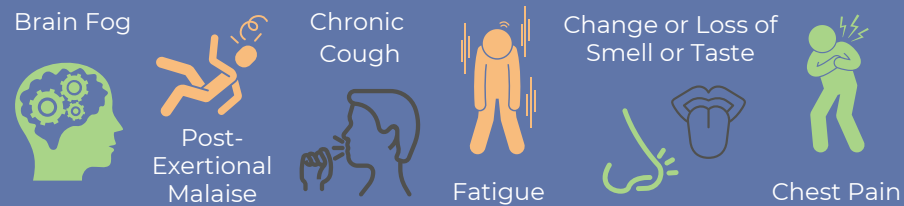
Identifying questions of interest to inform Long COVID Patient Registries

Adelaide Amah^{1,3,5} | Sarah Slagerman² | Pawan Kumar^{3,4,5} | Gary Groot^{4,5}

1 Saskatchewan Health Authority, 2 George & Fay Yee Centre for Healthcare Innovation, 3 Saskatchewan Centre for Patient-Oriented Research, 4 University of Saskatchewan, 5 Long COVID WEB

Background

Over 200 Long COVID (LC) symptoms have been documented by patients and researchers (1). Some examples include:



Objective

To determine what questions to include in a minimal data set to inform a National LC Patient Registry for harmonious data collection across Canada



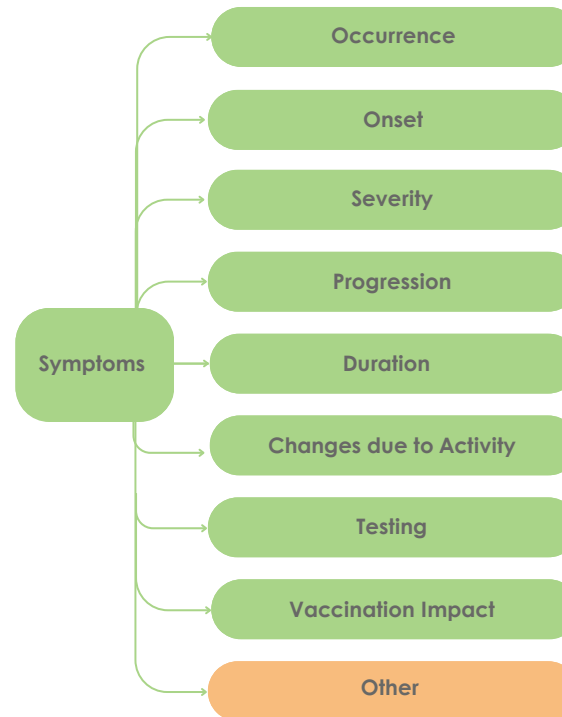
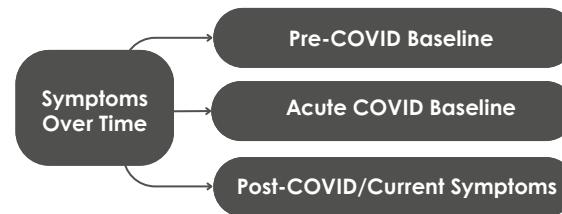
Methods

A literature search was conducted using PubMed and MEDLINE with pre-defined search criteria to collate a comprehensive repository of ~1500 LC survey questions being asked worldwide.

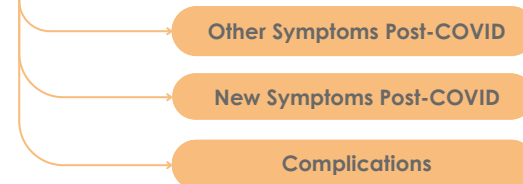


Sources were cited and examined for scope and objectives. All accessible LC survey questions were recorded along with the format used to collect responses (i.e., free fill, Likert Scale, multiple choice, etc.), and associated key words that could be used to locate similar surveys in secondary searches of the literature were also noted.

Results



[Figure 1: Symptoms of Long COVID question themes and categories]



Symptom Clusters

- Ear/Nose/Throat (5)
- Eyes (3)
- Digestive (3)
- General Symptoms (11)
- Genitourinary (2)
- Musculoskeletal/Locomotion (4)
- Neurological (11)
- Skin and Hair (4)
- Thorax (6)
- Vessels and Lymph Nodes (4)
- Mental Health (6)

[Figure 2: Symptoms reported by patients (n=1022) during the validation of the Long COVID Symptom and Impact Tools. Figure adapted from (2) with Mental Health added]

Future Directions

Our next steps will involve a team of LC experts, clinicians, researchers, patient partners and policy makers participating in a Delphi process to establish consensus regarding a LC minimum data set that could be used in Canada to inform the creation of a National LC Patient Registry.

References

1. Thaweethai T, Jolley SE, Karlson EW, Levitan EB, Levy B, McComsey GA, et al. Development of a Definition of Postacute Sequelae of SARS-CoV-2 Infection. JAMA. 2023 Jun 13;329(22):1934–46.
 2. Tran VT, Riveros C, Cleprier B, Desvarieux M, Collet C, Yordanov Y, et al. Development and Validation of the Long Coronavirus Disease (COVID) Symptom and Impact Tools: A Set of Patient-Reported Instruments Constructed From Patients' Lived Experience. Clin Infect Dis. 2022 Jan 15;74(2):278–87.
- References identified during the scan of the literature can be provided upon request.

Acknowledgements

This research was funded by the Saskatchewan Centre for Patient-Oriented Research (SCPOR), which receives financial and in-kind support from the Canadian Institutes of Health Research, Saskatchewan Health Authority (SHA), University of Saskatchewan, Saskatchewan Health Quality Council, Saskatchewan Health Research Foundation, First Nations University of Canada, eHealth Saskatchewan, University of Regina, Saskatchewan Polytechnic and Saskatchewan Cancer Agency. Additionally, we acknowledge the in-kind support received by George & Fay Yee Centre for Healthcare Innovation (CHI).

Research support services were provided by SHA Research Department and CHI's Evaluation and Quality Improvement Team. Project management and graphic design services were provided by Pawan Kumar and Renee Greene^{3,4} respectively.

The opinions, results and conclusions reported in this paper are those of the authors and are independent from the funding sources.



LONG COVID WEB