

Supplemental File 2

Questionnaire Administration (Qualtrics) Cover Page (Phase 2 – Time 1)



Physical Therapy  
UNIVERSITY OF TORONTO



## **Long COVID and Episodic Disability: Advancing the Conceptualization, Measurement and Knowledge of Episodic Disability with people living with Long COVID**

### **Step 1 of 2**

*\*To be formatted electronically in Qualtrics\**

**You are being asked to take part in the Long COVID and Episodic Disability Study.** The purpose of this study is to enhance understanding of the experiences of adults living with Long COVID, and to develop and assess a new questionnaire that can measure the types of disability experienced by people living with Long COVID, such as fatigue, pain, and challenges with day-to-day activities.

#### **WHY IS THIS RESEARCH BEING DONE?**

As the prevalence of Long COVID increases, more individuals are living with ongoing physical, mental and social health challenges after COVID-19 infection, known as **disability**. Questionnaires designed to capture this disability are important for health providers to understand the disability experienced so that they can provide care. Our research team has previously developed questionnaires in the context of adults living with HIV in Canada, United States, Ireland and United Kingdom. We hope to build on this work and apply lessons learned in other chronic and episodic conditions to understand and conceptualize disability experienced among adults living with Long COVID.

#### **WHAT IS THE PURPOSE OF THIS STUDY?**

The purpose of this study is to gain a better understanding of the disability experiences among people living with Long COVID, to develop the Episodic Disability Questionnaire (EDQ), and assess how well this questionnaire can measure disability in people living with Long COVID.

#### **WHO IS CONDUCTING THIS STUDY?**

The team conducting this study includes people living with Long COVID, people affiliated with COVID support networks, and researchers and clinicians working in COVID-19 care in Canada, United Kingdom, United States, and Ireland. This study involves participants living with Long COVID in all four countries. University of Toronto (Canada) is the primary site of the study.

#### **WHO CAN PARTICIPATE?**

Adults (18 years or older) living with Long COVID able to read and understand English.

Date Last Revised: November 5, 2021

1

## Supplemental File 2

## Questionnaire Administration (Qualtrics) Cover Page (Phase 2 – Time 1)

**WHAT IS INVOLVED BY TAKING PART IN THIS STUDY?**

This study involves two steps. If you choose to participate, you will be asked to complete a web-based survey including the **Episodic Disability Questionnaire** followed by 5 general health status and demographic questionnaires including:

- World Health Organization Disability Assessment Schedule (WHODAS 2.0)
- COVID-19 Yorkshire Rehabilitation Scale (C19-YRS)
- Health-related quality of life (EQ5D-5L)
- Work and Social Adjustment Scale (WSAS)
- Demographic and Health Questionnaire

One week later, you will be emailed a link to complete the EDQ only, again a second time along with a question about whether your health status changed in the past week (yes/no). This will allow us to see how consistent the EDQ is at measuring health challenges over time.

**HOW LONG WILL THIS TAKE?**

We estimate that it will take approximately 30 minutes to complete all the questionnaires in Week 1, and approximately 5 minutes to complete the EDQ the second time at Week 2.

Answers to the questionnaires will be confidential and stored on a secure computer at the University of Toronto (Canada). We will not link your name or any other information that identifies you to your questionnaire responses.

**WHAT ARE THE POSSIBLE RISKS?**

There are no obvious risks if you decide to be in this study. There may be unforeseen risks. It is possible that you may find some questions to be personal or uncomfortable to answer. You may choose not to answer questions for any reason and you may stop or take breaks during the survey at any time. If you become upset when filling out the questionnaires, the researchers encourage you to follow up with your health care professional (e.g. physician), qualified counselor, or services at the relevant community site/network.

**WHAT ARE THE POSSIBLE BENEFITS?**

You may or may not benefit from participating in this research study. Taking part in this study will not give you any direct health benefits. However, knowledge gained from this study may help to advance the field of rehabilitation in the context of Long COVID. Results from this study may directly help to develop a disability questionnaire and advance knowledge about disability that adults living with Long COVID experience.

**IF I START THE SURVEY, CAN I STOP?**

Completing the questionnaires is voluntary. You can stop at any time. We do not expect the questions to be upsetting, but if you become upset or bothered while completing the questionnaires, you can stop. If your concerns persist, please contact your health care provider or local community health centre, or reach out to the research team for further information

## Supplemental File 2

## Questionnaire Administration (Qualtrics) Cover Page (Phase 2 – Time 1)

about supportive services in your area. Choosing to withdraw from the study will not compromise any care you receive through any COVID-19 support networks/services.

**WILL I BE PAID TO PARTICIPATE IN THIS STUDY?**

You will not be paid to take part in this research study, but after completing the study, you can receive a \$30 CAD gift card (or equivalent) to thank you for participation completing the questionnaires. You will receive the gift card at the end of your participation in the study, after Step 2, when you complete the EDQ the second time. If you choose to withdraw from the study prior to Step 2, you may still obtain the token of appreciation.

**WHO IS FUNDING THE STUDY?**

This study is funded by the Canadian Institutes of Health Research (CIHR), Emerging COVID-19 Research Gaps and Priorities Funding Opportunity (FRN: GA4-177753).

**HOW CAN I GET A SUMMARY OF THE STUDY RESULTS?**

All data / publications resulting from the study will be made open access / publicly available. Any available data will be in aggregate form without any personal identifiers to protect the anonymity of participants. A summary of the results and publications from this study will be available on the Long COVID Physio website: <https://longcovid.physio>.

**WHO CAN I CONTACT IF I HAVE ANY QUESTIONS?**

If you have any questions about the research study, please contact Kelly O'Brien (Co-Principal Investigator) at [kelly.obrien@utoronto.ca](mailto:kelly.obrien@utoronto.ca) or 416-946-3935, or Brittany Torres (Research Coordinator) at [brittany.torres@utoronto.ca](mailto:brittany.torres@utoronto.ca) or 416-946-3935. If you have any questions regarding your rights as a research participant please contact the Research Oversight and Compliance Office - Human Research Ethics Program at [ethics.review@utoronto.ca](mailto:ethics.review@utoronto.ca) or 416-946-3273.

**OK, let's start.**

**Click on the Next>> button below to continue.**

Supplemental File 2

Questionnaire Administration (Qualtrics) Cover Page (Phase 2 – Time 1)

## Eligibility / Consent Page

Thank you for your interest in the **Long COVID and Episodic Disability Study**. Before you start, please read the following statements and indicate your answer to each one.

E01. I am at least 18 years of age.

- Yes
- No

E02. I am a person living with Long COVID.

- Yes
- No

E03. I am currently living in Canada / United States / Ireland / United Kingdom.

- Yes
- No

E04. I agree to participate in this research study.

- Yes
- No



**Your responses indicate that you are eligible and willing to participate in this research study!**

Date Last Revised: November 5, 2021

Supplemental File 2

Questionnaire Administration (Qualtrics) Cover Page (Phase 2 – Time 1)

You indicated you are at least 18 years of age, living with Long COVID, currently living in Canada [insert site country here] and you agree to participate in this research study.

**Please click on the Next>> button below to continue.**

**[Next 2 items are conditional if E01-E04 is 'yes']**

E05. What is your **participant ID #?** (You received this number from the study coordinator).

\_\_\_\_\_

E06. What is today's date? [insert into calendar]

## Instructions

### Instructions for Completing the EDQ and Health Questionnaires

Thank you for agreeing to participate in the **Long COVID and Episodic Disability Study**. You will be directed to the questionnaires. Please read the instructions carefully for each questionnaire. There are no right or wrong answers. Choose the most accurate answer for YOU. Don't worry about what other people might say. And don't worry about what you think others might want you to say. It should take approximately 30 minutes to complete all questionnaires.

Please answer every question.

To go through the questionnaires, you must use the "<<Previous" and "Next>>" buttons at the bottom of the screen. Thank you!

Date Last Revised: November 5, 2021

Supplemental File 2

Questionnaire Administration (Qualtrics) Cover Page (Phase 2 – Time 1)

*[After the questionnaires – End Page]*



**Thank you for your participating in the Long COVID and Episodic Disability Study.**

### **Next Step for the EDQ Study**

In one week, we will email you a link to complete only the **Episodic Disability Questionnaire (EDQ)** again. This is to see how consistent the EDQ is at capturing your health challenges over time.

**If you have any questions**, please contact Kelly O'Brien (Co-Principal Investigator) at [kelly.obrien@utoronto.ca](mailto:kelly.obrien@utoronto.ca) or 416-946-3935, or Brittany Torres (Research Coordinator) at [brittany.torres@utoronto.ca](mailto:brittany.torres@utoronto.ca) or 416-946-3935. If you have any questions regarding your rights as a research participant please contact the Research Oversight and Compliance Office - Human Research Ethics Program at [ethics.review@utoronto.ca](mailto:ethics.review@utoronto.ca) or 416-946-3273.



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Date Last Revised: November 5, 2021

6