

Supplemental File 3

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



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

Step 2 of 2

To be formatted electronically in Qualtrics

We thank you again for completing the first step of the Long COVID and Episodic Disability Study and welcome you to the final step of the study. As previously mentioned, 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. This stage involves completing the Episodic Disability Questionnaire (EDQ) a second time (one week after you first completed it), so we can determine how consistent the EDQ is at capturing your health challenges over time.

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.

HOW LONG WILL THIS STEP TAKE?

We estimate that it will take approximately 5 minutes to complete the EDQ this second time. Answers to the questionnaire will be confidential and stored on a secure computer at the University of Toronto (Canada).

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 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.

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WILL I BE PAID TO PARTICIPATE IN THIS STUDY?

You will not be paid to take part in this research study, but after completing this final questionnaire, you can receive a \$30 CAD gift card (or equivalent) to thank you for participation completing the questionnaires. If you choose to withdraw from the study, you may still obtain the token of appreciation. After completion of this questionnaire, a member of the research team will contact you about your gift card.

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 or 416-946-3935, or Brittany Torres (Research Coordinator) at 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 or 416-946-3273.

OK, let's start.

Click on the Next>> button below to continue.

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Eligibility / Consent Page

Thank you for your interest in the **Long COVID and Episodic Disability Study**. Before you start, please read the following statement carefully and indicate your answer.

E01. I **agree to complete the EDQ (questionnaire)** for this **second phase of the study**.

- Yes
- No



Your response indicates that you are willing to participate in Step 2 of this research study!

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

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

E02. What is your **participant ID #?** (You received this number from the study coordinator).

E03. What is today's date? [insert into calendar]

E04. Has your health status changed in the past week (since you completed the questionnaire a week ago)?

- Yes
- No

[Next item is conditional if E04 is 'yes']

E04b: You indicated your health status has changed. What changes have occurred?

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Instructions

Instructions for Completing the EDQ

Thank you for agreeing to participate in the **Long COVID and Episodic Disability Study**. You will be directed to the EDQ Questionnaire. Please read the instructions carefully for each question. 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 5 minutes to complete the questionnaire.

Please answer every question.

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

[After the questionnaires – End Page]



**Thank you for completing the Episodic Disability Questionnaire (EDQ)
and for your participation in the Long COVID and Episodic Disability
Study.**

Next, we will ask you some final questions.

1a. Would you be willing to **participate in future phases** of research related to Long COVID and Episodic Disability?

- Yes
 No

2b. What **email address** would you like us to reach you for future research?

Email Address: _____

SUBMIT (button)

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**You have completed the Long COVID and Episodic Disability Study!
Thank you for participating in this study.**

If you have any questions, please contact Kelly O'Brien (Co-Principal Investigator) at kelly.obrien@utoronto.ca or 416-946-3935, or Brittany Torres (Research Coordinator) at 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 or 416-946-3273.



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