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Long COVID and episodic disability: advancing the conceptualisation, measurement and knowledge of episodic disability among people living with Long COVID – protocol for a mixed-methods study

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ABSTRACT

Introduction As the prevalence of Long COVID increases, there is a critical need for a comprehensive assessment of disability. Our aims are to: (1) characterise disability experiences among people living with Long COVID in Canada, UK, USA and Ireland; and (2) develop a patient-reported outcome measure to assess the presence, severity and episodic nature of disability with Long COVID.

Methods and analysis In phase 1, we will conduct semistructured interviews with adults living with Long COVID to explore experiences of disability (dimensions, uncertainty, trajectories, influencing contextual factors) and establish an episodic disability (ED) framework in the context of Long COVID (n~10 each country). Using the conceptual framework, we will establish the Long COVID Episodic Disability Questionnaire (EDQ). In phase 2, we will examine the validity (construct, structural) and reliability (internal consistency, test–retest) of the EDQ for use in Long COVID. We will electronically administer the EDQ and four health status criterion measures with adults living with Long COVID, and readminister the EDQ 1 week later (n~170 each country). We will use Rasch analysis to refine the EDQ, and confirm structural and cross-cultural validity. We will calculate Cronbach's alphas (internal consistency reliability), and intraclass correlation coefficients (test–retest reliability), and examine correlations for hypotheses theorising relationships between EDQ and criterion measure scores (construct validity). Using phase 2 data, we will characterise the profile of disability using structural equation modelling techniques to examine relationships between dimensions of disability and the influence of intrinsic and extrinsic contextual factors. This research involves an academic–clinical–community partnership building on foundational work in ED measurement, Long COVID and rehabilitation.

Ethics and dissemination This study was approved by the University of Toronto Research Ethics Board. Knowledge translation will occur with community collaborators in the form of presentations and publications in open access peer-reviewed journals and presentations.

Strengths and limitations of this study

- ► Our combined qualitative and quantitative approaches will ensure a comprehensive exploration of experiences among diverse Long COVID populations across healthcare contexts.
- ► Collaborating with international community networks will provide a robust sampling frame enabling timely recruitment to achieve our sample size, immediate comparisons and rapid uptake of evidence.
- ► This study draws on a strong conceptual foundation of episodic disability (Episodic Disability Framework) and measurement of disability (Short Form-Episodic Disability Questionnaire) developed using community-engaged approaches with HIV as an exemplar of episodic illness.
- ► Our cross-sectional nature of the qualitative interviews may limit our ability to document the episodic nature of disability for people living with Long COVID.
- ► Our ability to attain a representative diverse sample of people with Long COVID given our likelihood to recruit individuals who experience fewer and less severe cognitive and postexertional challenges.

INTRODUCTION

A growing number of individuals are living with persistent and prolonged signs and

symptoms following infection consistent with COVID-19,[1 2] referred to as post-COVID-19 condition or Long COVID.[3 4] Post-COVID-19 condition occurs in children and adults with a history of probable or confirmed SARS CoV-2 infection, usually 3 months from the onset of COVID-19, with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis.[3] Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Systematic review evidence examining symptoms among individuals after COVID-19 reported 38%–72% were living with ≥1 symptom for at least 2 months from COVID-19 onset[5–9] and up to 54% living with symptoms at 6 or more months.[9] Common symptoms include fatigue, weakness, breathlessness, postexertional symptom exacerbation and cognitive or concentration impairment that can impact daily function[2 3 6–10] and can occur regardless of severity of acute COVID-19.[11 12] Additional challenges with return to employment, relationships, accessing services and stigma, can further contribute to disability after acute COVID-19.[13–18] Men and women can experience disability differently pertaining to hospitalisation, parental roles, fatigue, mental health and social inclusion.[19–22] Long COVID may further disproportionately affect people from racialised communities and those with pre-existing comorbidity.[22–26] With the 'severely disabling'[16] potential of Long COVID, the role for rehabilitation is critical.[27–30] As such, it is imperative to conceptualise disability in Long COVID and to establish tools to accurately measure disability to inform timely and appropriate access to rehabilitation approaches, and inform policies that consider the complexities of Long COVID.[16 31 32]

Long COVID is multidimensional, episodic and unpredictable, characterised by 'clusters of symptoms' that can overlap and 'fluctuate and change over time', described as 'prolonged', 'relapsing and remitting'.[3 17 33–38] These characteristics resemble episodic disability (ED), a concept derived from the context of HIV, where health challenges can fluctuate daily or over longer periods of time.[39 40] There is an opportunity to apply lessons learnt in other chronic and episodic illnesses to understand and conceptualise the disability experienced among adults living with Long COVID.

Members of this team developed the Episodic Disabiltiy (ED) Framework to characterise this multidimensional and sometimes fluctuating nature of health-challenges living with HIV.[39 41] The Episodic Disability Framework includes: (1) dimensions of disability (physical, cognitive, mental and emotional health, daily activities, social inclusion and uncertainty—similar to those reported in Long COVID)[2 37 42]; (2) contextual factors, which include extrinsic (eg, support, environment) and intrinsic (living strategies; personal attributes) factors that influence disability and (3) triggers, that can exacerbate a momentous episode.[39 41] Empirically validated with adults living with HIV in Canada[43] and Ireland,[44] and the first of its kind in the field, the Episodic Disability Framework provides a novel method for conceptualising the multidimensional nature of living with chronic illness by capturing experiences of uncertainty and the temporal (fluctuating) feature of disability over time.[43] Using this existing framework of disability rigorously developed from others living with episodic illness can provide a foundation for understanding disability experienced by people living with Long COVID.[38]

Standardised patient-reported outcome measures (PROMs) designed to capture the nature and extent of disability and its fluctuation over time are critical to guide the provision of care, determine the effectiveness of interventions, and inform workplace policies, benefits and access to services for people with Long COVID.[16 17] Current disability measures used in Long COVID[45 46] lack items related to uncertainty,[33] do not capture the fluctuating nature, and were not derived or validated with or from the perspectives of people living with Long COVID. Members of our team developed the HIV Disability Questionnaire (HDQ) a PROM[47 48] which describes a range of health challenges a person might experience and the extent of fluctuation, so clinicians may better understand and address the disability needs of people with chronic illness. This tool is the first known measure of Episodic Disability, addressing gaps in previously existing health status measures to capture uncertainty and elements of social inclusion (relationships, employment).[49] The HDQ possesses reliability and validity for use with adults living with HIV in Canada, Ireland, UK, and USA.[50–53] Recently, our team used modern psychometric (Rasch) and community-engaged approaches to establish a Short-Form version (SF-HDQ) to enhance the feasibility, electronic administration and immediate scoring for use in clinical and community settings.[54] The lessons learnt in HIV, disability and rehabilitation, specifically our work in Episodic Disability and PROM development provides a foundation for conceptualising and measuring Episodic Disability in the context of Long COVID.[33]

The goal of this study is to advance the conceptualisation and measurement of episodic disability among adults living with Long COVID to inform clinical practice, research and policy. Our specific aims are: (1) to conceptualise the disability experiences (dimensions, trajectories, contextual factors and triggers that exacerbate or alleviate disability over time) among people living with Long COVID in Canada, UK, USA and Ireland, and to establish the Episodic Disability Framework in the context of Long COVID; and (2a) to develop and (2b) assess the measurement properties of an Episodic Disability Questionnaire (EDQ) while (2c) collecting foundational data on the presence, severity and episodic nature of disability and contextual factors (sex, gender, race, age, comorbidity, country) that may influence disability among adults living with Long COVID in Canada, UK, USA and Ireland.

METHODS AND ANALYSIS

We will conduct an observational study using mixed methods to establish a conceptual foundation, and PROM, of episodic disability among adults living with Long COVID. We use 'living with Long COVID' throughout to refer to people with Long COVID, regardless of the present nature and severity of symptoms. In the context of this study, 'living with Long COVID' does not assume permanence or recovery, rather recognises the fluctuating, uncertain and potentially unpredictable nature of the course of Long COVID.

Study design

We will conduct a mixed-methods study using qualitative (aim 1) and quantitative measurement (aim 2) approaches with adults living with Long COVID in Canada, UK, USA and Ireland. Leveraging our work with the Episodic Disability Framework and SF-HDQ, we will examine the cross-cultural applicability and measurement properties of a new electronic (e)-PROM of episodic disability in Long COVID.

Patient and public involvement

This research involves an international community–academic–clinical partnership building on foundational work in episodic disability among an international team with expertise in episodic illness, disability, measurement, COVID-19, Long COVID and rehabilitation. This study draws from our work in lessons learnt from HIV for COVID-19 rehabilitation.[33 55] Building on our long-standing community-engaged research approach,[47 56] our study involves members of the Long COVID community who were involved in the conceptualisation of the research proposal and acquisition of funding as Collaborators and Knowledge Users. Our team includes people living with Long COVID and representatives from Long COVID community networks (Long COVID Physio, Patient-Led Research Collaborative, Long COVID Support, COVID Long-Haulers Support Group Canada and Long COVID Ireland)[57–61] who comprise a Community Advisory Committee (CAC) who co-lead and advise on all stages of the research, and coauthor publications and presentations.

Participants and recruitment

We will recruit individuals who self-identify as having a history of probable or confirmed SARS-CoV-2 infection, and new symptoms occurring within 3 months from the onset of COVID-19 that last for at least 2 months and cannot be explained by an alternative diagnosis.[3] We will include individuals irrespective of hospitalisation or confirmation of SARS-CoV-2 test (PCR, antigen or antibody). We will recruit adults from Canadian, British, American, Irish and international collaborating Long COVID support networks[57–61] via email and social media platforms. Community experts/collaborators on the team will lead recruitment as they are best positioned to identify individuals from the community who they identify as representing different characteristics (or combinations of characteristics). We will recruit for diversity in characteristics such as age, sex, gender, race, geographical setting (urban vs rural), employment/student status, socioeconomic status, hospitalisation and country, as able.

Aim 1: interviews

Community experts will circulate a recruitment poster to individuals in the Long COVID community networks that meet our inclusion and sampling criteria. Interested individuals will contact the respective research coordinator on the team who will send an email to individuals thanking them for interest in the study and attach a consent form for the interview (online supplemental file 1). We will relay information about the purpose and rationale of the study, inclusion criteria, potential of participation, the voluntary nature of the study and their right to withdraw at any time and compensation. On expression of interest, we will send a second email to schedule the one-on-one interview. We will send a third email with additional details, including Zoom information for joining the interview, 1 day prior to the interview.

Aim 2: questionnaire administration

We will recruit adults living with Long COVID from Canada, UK, USA and Ireland via community networks. Community collaborators will circulate a study poster with contact information for the relevant research coordinator through email or social media. We will apply our lessons learnt using community-engaged approaches with web-based surveys[62] and a modified Dillman Method[63] to email potential participants identified via our sampling frame, followed by follow-up reminder emails at 1, 2 and 4 weeks after the initial invitation to facilitate recruitment.

Interested individuals will contact the research coordinator for more information. Research coordinators will send an email that includes the details of the study, with an assigned participant number, and a Qualtrics link to the information cover page (with details of the study, eligibility and consent question) and if eligible/consent, the Time 1 (T1) study questionnaires. The cover page (online supplemental file 2) will include information about the purpose and rationale of the study, inclusion criteria, potential risks, the voluntary nature of the study, and compensation. If an individual participates in the study at T1, we will email a link for the T2 cover page and questionnaire (EDQ only) 1 week later (online supplemental file 3).

Research procedure

See figure 1 for an overview of the research procedures. Participants will be able to take breaks and schedule the interview or questionnaire completion over more than one session to prevent overexertion resulting postexertional malaise.

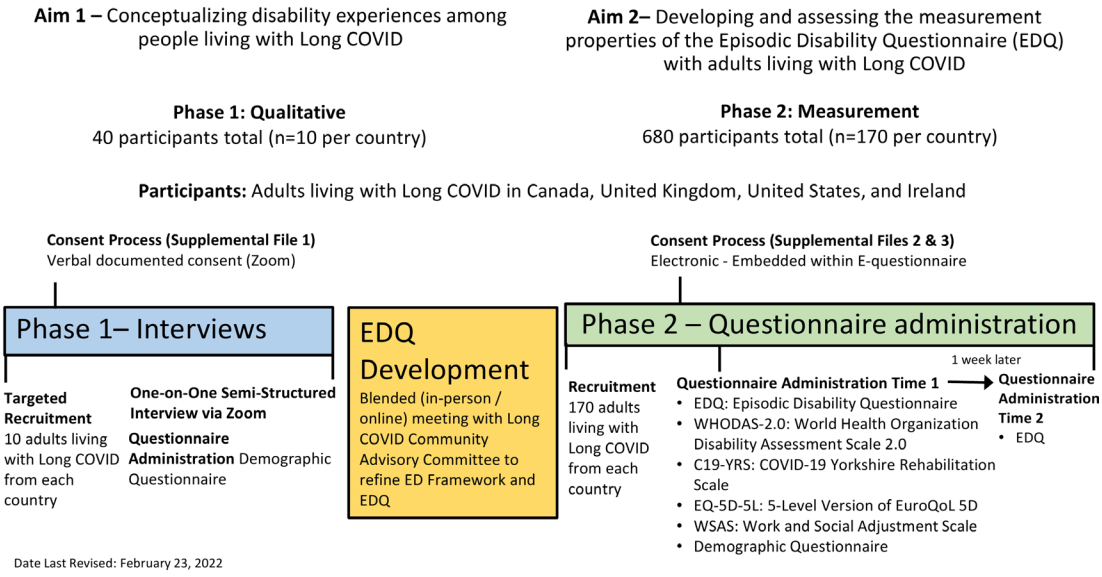

Figure 1 Overview of Research Procedure—Long COVID and Episodic Disability study.

Qualitative data collection (aim 1)

We will conduct semistructured online (Zoom) interviews with adults who self-identify as living with Long COVID to explore disability experiences and examine the extent to which the Episodic Disability Framework captures their health challenges across our four partner countries. Using an interview guide, we will explore: (1) health-related challenges (dimensions of disability: physical, cognitive, mental health, uncertainty, social inclusion, day-to-day activities); (2) trajectories and dimensions of disability experienced as episodic (fluctuating); (3) extrinsic and intrinsic contextual factors that influence disability (eg, comorbid conditions); (4) triggers that may exacerbate an episode and (5) impact (eg, employment, access to services, financial security). We will ask participants to draw their trajectory of health-related challenges (disability) living with Long COVID over time. We will refine the Framework to inform the modification of the EDQ.

Episodic Disability Questionnaire (EDQ) development (aim 2a)

Using our conceptual framework established in aim 1 we will develop the EDQ, to capture presence, severity and episodic nature of disability. We will host a blended (in-person/online) meeting in consultation with the Long COVID CAC composed of persons living with Long COVID, COVID-19 support networks, researchers and clinicians working in COVID-19 care to refine the Episodic Disability Framework and EDQ in preparation for implementation. Episodic Disability Questionnaire (EDQ) items will be derived from categories in the Framework (aim 1), adapted from the original SF-HDQ, and refined with the CAC.

Quantitative data collection (aim 2b and 2c)

We will electronically administer the Episodic Disability Questionnaire (EDQ) followed by four criterion measures currently used in Long COVID: WHO Disability Assessment Schedule,[45] COVID-19 Yorkshire Rehabilitation Scale (C19-YRS)[46]; EuroQol- EQ-5D-5L quality of life questionnaire,[64] Work and Social Adjustment Scale (WSAS)[65] using e-survey software (Qualtrics) at Time 1.[66] The EDQ (only) will be readministered electronically a second time, 1 week later (time 2). At time 2, we will ask participants whether they had any major changes in their health since Time 1 (to indicate consistency in disability for reliability assessment of the EDQ) (figure 1).

WHO Disability Assessment Schedule 2.0 (WHODAS 2.0)

The WHODAS 2.0 contains 36 items that measures disability across six domains (cognition, mobility, self-care, getting along, life activities and participation). Scores ranges from 0 to 100, where 0 means no disability and 100 means full disability. The WHODAS 2.0 possesses reliability, validity and responsiveness among people with chronic disease.[45]

COVID-19 Yorkshire Rehabilitation Scale

The C19-YRS is a digital assessment and monitoring tool that screens for some of the most common symptoms of Long COVID, including breathlessness, cough, fatigue, depression and anxiety.[45 67] The scale consists of 22 items with each item scored on an 11-point numerical rating scale from 0 (none of this symptom) to 10 (extremely severe level or impact). The C19-YRS is divided into four subscales (range of total score for each subscale): symptom severity score (0–100), functional disability score (0–50), additional symptoms (0–60) and overall health (0–10). The C19-YRS possesses internal consistency, content validity and clinical usefulness for use with persons with Long COVID.[67]

EuroQol EQ-5D-5L

The EQ-5D-5L is a measure of health-related quality of life widely used in cost effectiveness analysis. The EQ-5D-5L consists of 5 items (mobility, self-care, usual activities,

pain/discomfort, anxiety/depression) each with 5 levels of response options, followed by a visual analogue scale (overall health)[64] and has been utilized as a measure of quality of life in the context of COVID-19.[13 68]

Work and Social Adjustment Scale

The WSAS is a five-item questionnaire asking about the impact of a health condition on ability to work, home management, social leisure activities, private leisure activities and relationships with others.[65] The WSAS has demonstrated utility, reliability and validity as a measure of functional impairment for use with people with mental health conditions.

Demographic questionnaire

In aims 1 and 2 (time 1 only), we will administer a demographic questionnaire capturing factors such as: age, sex, gender, sexual orientation, race, country, employment status, multimorbidity, access to supports, living situation (alone vs not), COVID-19 vaccination status, severity of acute COVID-19 (non-hospitalised, hospitalised versus Intensive Care Unit (ICU)), timing of acute COVID-19, Long COVID symptom onset, and access to a Long COVID clinic.

Analysis

Interview data (aim 1)

We will analyse interviews using content analytical techniques[69] and a team based approach to qualitative analysis involving community collaborators.[70 71] Our coding scheme will be informed by the Episodic Disability Framework and include: (1) dimensions of health challenges; (2) factors that trigger, exacerbate or alleviate disability; (3) episodic nature of disability (trajectories); (4) uncertainty living with Long COVID and (5) contextual considerations (eg, country, gender). We will also allow additional codes to emerge to identify new features of disability with Long COVID. We will use NVivo software for data management.[72]

Episodic Disability Questionnaire (EDQ) development (aim 2a)

We will conduct a content analysis on the discussion notes taken from our consultation meeting with the Long COVID CAC to refine the Episodic Disability Framework (aim1) and Episodic Disability Questionnaire (EDQ).

Questionnaire data

We will calculate EDQ disability presence, severity and episodic (calculated for descriptive purposes only) across the six domains and total scores (transformed out of 100) for each time point. Higher scores indicate a higher presence, severity and episodic nature of disability. WHODAS 2.0 scores ranges from 0 to 100, where 0 means no disability and 100 means full disability. We will calculate mean (SD) and median (IQR) domain scores. The C19-YRS is divided into four subscales (range of total score for each subscale): symptom severity score (0–100), functional disability score (0–50), additional symptoms (0–60) and overall health (0–10). For the EQ5D-5L divide the dimensions into five levels of health problems to collectively represent a health state that represent each of the numerical descriptions.[64] For the WSAS, we will calculate a total score. A score above 20 suggests moderately severe or worse psychopathology, scores between 10 and 20 are associated with significant functional impairment but less severe clinical symptomatology, and scores below 10 are associated with subclinical populations. Individual severity scores are derived by summing the values (scores) for the six questions for each individual.[65] For the demographic questionnaire, we will calculate descriptive statistics including frequencies (%) for categorical variables and median and IQR for continuous variables.

Property assessment (aim 2b)

We will conduct Rasch analysis, a preferred method for developing PROMs, assessing structural and cross-cultural validity, and for establishing an interval-level scale.[73–76] We will use criteria for model fit similarly used in our SF-HDQ development[54]: Cronbach's alpha (internal consistency reliability (≥0.8 acceptable),[77] and Person Separation Indices (≥0.70 acceptable),[78] individual item fit using item threshold ordering, fit residuals (residuals >|2.5|),[79 80] differential item functioning (country, age, sex, gender)[74] and unidimensionality.[81] We will create a user-friendly scoring algorithm to convert raw summed EDQ scores to the equivalent Rasch-based person logit scores rescaled (0–100) with higher scores indicating greater severity of disability.[82]

We will assess test–retest reliability with ICC using time 1 and 2 EDQ scores (>0.8 acceptable).[77 83] We will examine correlations for a priori hypotheses theorising relationships between EDQ and criterion measure scores. Correlations of |≥0.30|, |≥0.50| and |≥0.70| will be defined as 'weak', 'moderate' and 'strong,' respectively.[84] Construct validity will be defined as >75% confirmed hypotheses.[85]

Disability profile (aim 2c)

We will use descriptive and structural equation modelling techniques to examine relationships between dimensions of disability and contextual factors.[86 87] We will conduct path analyses to determine relationships between dimensions of disability and contextual factors (sex, gender, age, race, multimorbidity, hospitalisation, country, acute disease severity, symptom clusters, vaccination status) in a stepwise fashion to determine how these factors influence disability. We will estimate parameter values using Maximum Likelihood Methods of Estimation.[88] We will assess overall goodness of fit (Root Mean Square Error of Approximation (<0.05), Comparative Fit Indices (≥0.95), Tucker Lewis Index (≥0.95)) and the magnitude and direction of the parameter estimates to determine overall fit of our model.[89–91] We will use SAS V 9.3,[92] RUMM2030[93] and Mplus statistical software[94] to facilitate analysis and discuss model interpretations and implications with the team.

Sample size

For aim 1, based on our previous work cross-cultural assessment of the Episodic Disability Framework,[51] we anticipate a sample of 40 across 4 countries (~10/country) will be sufficient to provide perspectives of disability internationally.[95] For aim 2, our sample size is based on the Rasch analysis (aim 2b). To maximise item parameter estimation precision with minimal root mean squared deviation, we require at least 500 observations.[96] To account for missing responses (~35%) at time 2 (test–retest), we will collect data on 680 participants (170 per country).

DISCUSSION

Results will yield the first known conceptual framework and PROM developed to assess the prevalence and impact of episodic disability in Long COVID. Specific outcomes will include: a conceptual framework (and definition) of Episodic Disability in the context of Long COVID; foundational knowledge on the profile and impact of episodic disability within Canadian, UK, USA and Irish Long COVID health contexts; a new e-PROM of episodic disability assessed for cross-cultural validity and reliability, poised for broad clinical and research use to enable future international comparisons; a guidance document for EDQ utility, administration and scoring; and a new and strengthened multidisciplinary and international team of clinicians, researchers, and community members dedicated to addressing research priorities in Long COVID and rehabilitation.

Our combined qualitative and quantitative approaches will ensure a robust exploration of diverse experiences across Long COVID populations and healthcare contexts. Results can inform strategies for targeting interventions, and policies for return to work, health and income benefits for people living with Long COVID. Discerning cross-cultural applicability of the ED Framework and EDQ will help to establish a common understanding of disability with Long COVID to facilitate future research and international comparisons. Collaborators, Long COVID Support (UK),[58] COVID Long-Haulers Support Group Canada,[57] Patient-Led Research Collaborative (US),[60] Long COVID Physio,[59] Long COVID Ireland[61] and Canada-International HIV and Rehabilitation Research Collaborative[97 98] will further leverage integrated knowledge translation.

This study addresses priorities outlined by the Long COVID community[99] and COVID-19 Rehabilitation Research Framework[100] highlighting the need to measure disability to inform best practices and policies for rehabilitation. The framework and Episodic Disability Questionnaire (EDQ) that emerges from this work may yield potential to lay the groundwork for future disability measurement in Long COVID and more broadly across other complex episodic illness.[55]

ETHICS AND DISSEMINATION

This protocol was approved by the University of Toronto Health Sciences Research Ethics Board (Protocol Reference #41749) on 17 November 2021.

Consent

Phase 1 (qualitative interviews)

Interested individuals will contact the coordinator in each country who will email them an overview of the study with the information/consent form (online supplemental file 1). The individual will be informed of the purpose and rationale of the study, inclusion criteria, potential medical and social risks of participation, the voluntary nature of the study and their right to withdraw at any time, and compensation. Verbal consent for the interview will be taken by the research investigator (over Zoom) at the time of the scheduled interview. The research team member will sign and date the consent form, confirming that verbal consent was obtained.

Phase 2 (questionnaire administration)

Research coordinators will send an initial recruitment email that includes the details of the study, a Qualtrics link to the information cover page. If individuals indicate they are eligible and consent to participate (in Qualtrics), they will be brought to the time 1 (T1) study questionnaires. If an individual participates in the study at T1 (consents to participate and completes the T1 questionnaires), we will email a link for the T2 questionnaire (EDQ only) 1 week later. T1 and T2 cover pages include an electronic eligibility/consent form for participants to complete prior to proceeding with the questionnaire(s). Consent will also be implied with completion of the questionnaires (online supplemental file 2) (T1 cover page) and (online supplemental file 3) (T2 cover page).

Token of appreciation

Participants living in Canada, USA, UK and Ireland will be provided with a $C30, US$20, £15 gift card and €20, respectively, as a token of appreciation for participation in the interview and completion of the demographic questionnaire (phase 1). We will provide participants with a similar token of appreciation for completing both time 1 and 2 questionnaires (phase 2).

Potential risks and benefits

Some adults living with Long COVID may find the interview or questionnaire completion to be cognitively demanding. Participants will be able to take breaks and schedule the interview or questionnaire completion over more than one session. Some of the questions on the questionnaires or in the interviews may be personal or sensitive in nature. Participants can choose not to answer questions and may end the interview or close their browser with the questionnaires on Qualtrics at any time. Interviewers will send participants a follow-up check-in email with contact information for the principal investigator (country lead) and for supportive services at specific community collaborator networks.

There are no direct benefits to participants taking part in this study. However, it may help to develop a new measure of disability and advance knowledge about the disability that adults living with Long COVID experience.

Confidentiality & Data Management

All participant records will be identified by a coded number to maintain confidentiality. A master list of participants with their respective participant numeric codes and contact information will be stored on a password-protected computer file by the investigator in the respective country. The master file linking participant names and email addresses to their number will remain in their country of origin. Electronic copes of the phase 1 (interview) consent forms will be stored on a secure server at the University of Toronto (Canada).

On completion of the interviews, we will immediately upload audio files to Sharefile, a password-protected secure sharing and encrypted transfer system.[101] Recordings will be deleted from the recording device and identification numbers will replace participant identifiers on corresponding data.

All questionnaire responses will be downloaded from Qualtrics, an online secure e-survey software that uses Transport Layer Security encryption,[66] and transferred to the University of Toronto using Sharefile,[101] and stored on a secure server at the University of Toronto. Anonymised data will be shared among investigators using Sharefile. Electronic data will be stored on a password-protected computer in a locked office at the University of Toronto and will be accessible only to investigators and research coordinators. Data will be anonymised when compiling and disseminating results. An anonymised aggregated dataset for this study will be made open access as per the funding conditions of the Canadian Institutes of Health Research via the University of Toronto.

Following the completion of the study, printed and electronic data (excluding audio recorded data) will be retained for 10 years in the same location that it was stored throughout the study. Audio files will be destroyed immediately following publication. Files containing personal contact information will be deleted after publication. All remaining electronic and hard copy data and information related to the study will be retained for 10 years after the completion of the study and then destroyed by the principal investigator (Toronto).

Dissemination

We will translate results among people living with Long COVID, researchers, clinicians and community organisations. Integrated knowledge translation will be led by the community advisory community and facilitated by community networks and organisations. We will develop an Episodic Disability and Long COVID Toolkit, shared widely with researchers, community groups and clinicians that will include approaches for conceptualising disability for people living with Long COVID. Further knowledge translation will occur via publications in open access peer-reviewed scientific journals, presentations at academic conferences, community organisations, webinars and education of trainees, in partnership with community collaborators.

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Correction notice This article has been corrected since it was first published. The figure has been updated.

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Contributors KKO'B and DAB co-led the conceptualisation of the study objectives, and drafted the protocol, lead the application for acquisition of funding and are the co-lead investigators on the study. KKO'B, DAB, JV, CBe and KME, JV are coprincipal investigators and country leads on the research team, and were involved in the conceptualisation of the study design, development of the protocol and acquisition of funding. LA, SCC, AC, LR, RH and PS are coinvestigators and were involved in the conceptualisation of the study design and contributed to the development of the protocol, and acquisition of funding. SG, LM, MO'H, CT, HW, RS and NR are collaborators and community experts in the Long COVID community who were involved in the review and refinement of the protocol. They are members of the Community Advisory Committee and will lead recruitment of participants and community-integrated knowledge translation. PG is a community collaborator and knowledge translation expert who will be involved in the knowledge translation. NSC-S and BT are research coordinators involved in the recruitment and data collection and contributed to the refinement of the protocol. CBa is a clinician working in Long COVID and coinvestigator who recently joined the team and

who reviewed of the protocol. All authors read and approved the final protocol manuscript.

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Supplemental File 1
Interview Consent Form - Example (Phase 1)

Information and Agreement Form to Participate in Study

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

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Community Collaborators
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Long Haulers Support Group of Canada - Susie Goulding
Patient-Led Research Collaborative - Hannah Davis, Lisa McCorkell, Hannah Wei
Long COVID Physio - Catherine Thompson, Darren Brown, Kelly O'Brien
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INTRODUCTION

You are being asked to take part in a research study about disability experienced by adults living with Long COVID. 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. Your participation will help to inform researchers on the use of this questionnaire and its ability to help refer people living with Long COVID to services and improved goal setting and communication between patients and their health providers. This research is a collaboration between researchers in Canada, United Kingdom (UK), United States (US), and Ireland.

In order to decide whether you want to be a part of this research study, you should understand what is involved and the potential risks and benefits. This form gives detailed information about the research study, which will be discussed with you. If you have any questions after reviewing this information letter and consent form, please do not hesitate to ask. If you understand the parts of the study and want to participate, you will be asked to sign a consent form (or verbally agree to participate and your consent will be documented by the study coordinator on the consent form).

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, US, Ireland and UK. 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, US, Ireland, and UK. This study will involve participants living with Long COVID in all four countries. University of Toronto (Canada) is the primary site of the study.

Supplemental File 1
Interview Consent Form - Example (Phase 1)

WHAT IS INVOLVED BY TAKING PART IN THIS STUDY?

One-on-One Interview: If you agree to take part in this study, you will be asked to participate in an interview approximately 60 minutes in duration whereby you will be asked questions about your health-related challenges living with Long COVID. The interview will include questions about your physical, mental, emotional, and cognitive challenges, how these challenges might fluctuate over time, and what triggers or helps your challenges improve. Lastly, you will be asked about any strategies or services you use to deal with the challenges you face.

The interview discussion will be used to develop this new measure of disability for adults living with Long COVID. A member of the research team will facilitate the interview through Zoom. The interview will be audio-recorded (using an audio recorder) and later typed out word for word with any names or personal identifiers removed.

Demographic Questionnaire: At the end of the interview, you will be asked to complete an web-based demographic questionnaire, which will include questions about various factors, such as sex, gender, race, health conditions you might be living with in addition to Long COVID, past hospitalizations, timing of acute COVID-19 diagnosis, and symptom onset. This questionnaire will take approximately 10 minutes to complete.

The interview is the first phase of this research study. There is a second phase of this research which involves completion of additional questionnaires. If you are interested in this second phase as well, please indicate your interest when you complete your consent form.

WHAT INFORMATION WILL BE KEPT PRIVATE?

Computer files containing the interview files and questionnaire responses will be stored on a secure server hosted by the University of Toronto. Consent forms will be uploaded and stored on the secure server at the University of Toronto (or respective site in the country of participation). Only researchers and advisors directly involved with the study will be able to access these files.

Audio files from the interviews will immediately be transferred from the recording device to a secure, online storage site with password protection. The files on the recorded device will then be deleted. Audio files will be deleted from the online storage site after the study is published, and all paper and electronic files will be destroyed ten years after the study is completed.

The one-on-one interview will take place virtually through Zoom. Any information you provide throughout your participation in the study, including contact information, recordings from the interview and questionnaire responses will be kept strictly confidential and only be made available to the research team and members of the University of Toronto Research Ethics Board who have reviewed the study. No information that would identify you (such as your name) will be recorded on any of our documents. For example, you will be assigned a specific numerical code that will be used to refer to you instead of your name. Only the researchers and investigators will have access to the meaning of this code and it will not be shared with anyone else. We will not include any personal information such as your name that could identify you in any of the publications or presentations related to this study.

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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 in the one-on-one interview personal or uncomfortable to answer. You may choose not to answer questions for any reason and you may stop taking part in the one-on-one interview at any time. Additionally, if you feel you would benefit from having the interview broken up into multiple sessions, this can be arranged with the interviewer. If you become upset during the one-on-one interview or when filling out the questionnaire, the researchers will encourage you to follow up with your health care professional (e.g. physician), qualified counselor, or services at the relevant community site/network, and can provide you with the contact information for support services relevant to your area. Further, the research team will follow up with all participants via email after the interview and will include the contact information for the Principal Investigator / site lead and the relevant community collaborator network should the participant require these services. Choosing to withdraw from the study will not compromise any care you receive through any COVID-19 support networks/services.

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.

WILL I BE PAID TO PARTICIPATE IN THIS STUDY?

You will not be paid to take part in this research study, but you will be given a $30 CAD dollar gift card as a token of appreciation to thank you for your participation in completing the one-on-one interview and questionnaire. If you choose to withdraw from the study during the interview, you will still receive the gift card.

WHAT WILL HAPPEN TO THE INFORMATION FROM THIS STUDY?

The researchers will submit a manuscript for open-access publication as well as communicate the knowledge gained from this study to researchers, health-care providers, community-based organizations and policy makers. Knowledge translation updates will be provided in the form of presentations, slides, fact sheets and social media. This information will also be presented at community organizations and clinics encouraging practical application of the results. Fact sheets of the results will be distributed by email if requested and as handouts. If you are interested in receiving a copy of the fact sheets and publications from the study investigators, you can contact Kelly O'Brien at kelly.obrien@utoronto.ca. All data/publications related to the study will be open access (available to anyone) as a condition of the study's funding in accordance with the joint statement on sharing research data and findings relevant to the novel coronavirus outbreak. Any available data will be in aggregate form, without any personal identifiers to protect the anonymity of participants. A summary of the study results and publications will be openly available on the Long COVID Physio website: https://longcovid.physio.

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IF I HAVE ANY QUESTIONS OR CONCERNS, WHOM CAN I CONTACT?

If you have any questions about the research study, please contact Kelly O'Brien (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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Interview Consent Form - Example (Phase 1)

CONSENT TO PARTICIPATE

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

I have read and understood all of the above. Signing this form does not waive my legal rights or relieve the investigator or sponsors from their legal and professional responsibilities.

I agree and consent to participating in completing the self-reported questionnaire and one-on-one interview.

By signing or giving verbal consent below I am agreeing that:

- I understand the information provided for the above study.
- I have had the opportunity to consider the information, ask questions and have had these questions answered satisfactorily.
- I understand that my participation is voluntary and that I am free to stop the study at any time without punishment.
- I understand that the data collected during the study may be looked at by responsible individuals from the research team, or the regulatory authorities where it is relevant. I give permission to these individuals to have access to the information I provided.
- I agree to participate in the above study.
- For the interview, I agree to be audio recorded.
- I have been provided with a copy of the consent form.

❑ **Provision of written consent**

_____	_____	_____
Participant's Name (please print)	Participant's Signature	Date

❑ **Provision of verbal consent**

_____	_____	_____
Witness' Name (please print)	Witness' Signature	Date

I am willing to be contacted about **future phases of the study** by email or phone.

❑ Yes, Contact: _____
❑ No

Date Last Revised: November 5, 2021

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

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

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 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.

Date Last Revised: November 5, 2021

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!

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

[After the questionnaires – End Page]

Physical Therapy
UNIVERSITY OF TORONTO

EDQ

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 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.

CIHR IRSC

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

Date Last Revised: November 5, 2021

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.

Date Last Revised: November 5, 2021

Supplemental File 3
Questionnaire Administration (Qualtrics) Cover Page (Phase 2 – Time 2)

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?
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OK, let's start.
Click on the Next>> button below to continue.

Date Last Revised: November 5, 2021

Supplemental File 3
Questionnaire Administration (Qualtrics) Cover Page (Phase 2 – Time 2)

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?

_____

Supplemental File 3
Questionnaire Administration (Qualtrics) Cover Page (Phase 2 – Time 2)

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)

4

Date Last Revised: November 5, 2021

Supplemental File 3
Questionnaire Administration (Qualtrics) Cover Page (Phase 2 – Time 2)

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.

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

Date Last Revised: November 5, 2021

Supplemental File 1
Interview Consent Form - Example (Phase 1)

Information and Agreement Form to Participate in Study

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

Co-Principal Investigator:
Kelly O'Brien, PhD, BScPT
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M5G 1V7
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Co-Principal Investigator:
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Research Team
Colm Bergin (Co-Principal Investigator, St James's Hospital)
Darren Brown (Co-Principal Investigator and Principal Knowledge User, Chelsea and Westminster Hospital NHS Trust)
Kristine Erlandson (Co-Principal Investigator, University of Colorado Denver)
Jaime Vera (Co-Principal Investigator, University of Sussex)
Lisa Avery (Co-Investigator, University Health Network)
Soo Chan Carusone (Co-Investigator, McMaster University)
Angela Cheung (Co-Investigator and Collaborator, Toronto General Research Institute and University Health Network)
Richard Harding (Co-Investigator, King's College London, Cicely Saunders Institute)
Larry Robinson (Co-Investigator, Sunnybrook Health Sciences Centre)
Patricia Solomon (Co-Investigator, McMaster University)

Community Collaborators
Long COVID Support, UK - Margaret O'Hara
Long Haulers Support Group of Canada - Susie Goulding
Patient-Led Research Collaborative - Hannah Davis, Lisa McCorkell, Hannah Wei
Long COVID Physio - Catherine Thompson, Darren Brown, Kelly O'Brien
Long COVID Ireland – Niamh Roche, Ruth Stokes
Canada-International HIV and Rehabilitation Research Collaborative (CIHRRC) - Patriic Gayle

Date Last Revised: November 5, 2021

Supplemental File 1
Interview Consent Form - Example (Phase 1)

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

INTRODUCTION

You are being asked to take part in a research study about disability experienced by adults living with Long COVID. 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. Your participation will help to inform researchers on the use of this questionnaire and its ability to help refer people living with Long COVID to services and improved goal setting and communication between patients and their health providers. This research is a collaboration between researchers in Canada, United Kingdom (UK), United States (US), and Ireland.

In order to decide whether you want to be a part of this research study, you should understand what is involved and the potential risks and benefits. This form gives detailed information about the research study, which will be discussed with you. If you have any questions after reviewing this information letter and consent form, please do not hesitate to ask. If you understand the parts of the study and want to participate, you will be asked to sign a consent form (or verbally agree to participate and your consent will be documented by the study coordinator on the consent form).

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, US, Ireland and UK. 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, US, Ireland, and UK. This study will involve participants living with Long COVID in all four countries. University of Toronto (Canada) is the primary site of the study.

Supplemental File 1
Interview Consent Form - Example (Phase 1)

WHAT IS INVOLVED BY TAKING PART IN THIS STUDY?

One-on-One Interview: If you agree to take part in this study, you will be asked to participate in an interview approximately 60 minutes in duration whereby you will be asked questions about your health-related challenges living with Long COVID. The interview will include questions about your physical, mental, emotional, and cognitive challenges, how these challenges might fluctuate over time, and what triggers or helps your challenges improve. Lastly, you will be asked about any strategies or services you use to deal with the challenges you face.

The interview discussion will be used to develop this new measure of disability for adults living with Long COVID. A member of the research team will facilitate the interview through Zoom. The interview will be audio-recorded (using an audio recorder) and later typed out word for word with any names or personal identifiers removed.

Demographic Questionnaire: At the end of the interview, you will be asked to complete an web-based demographic questionnaire, which will include questions about various factors, such as sex, gender, race, health conditions you might be living with in addition to Long COVID, past hospitalizations, timing of acute COVID-19 diagnosis, and symptom onset. This questionnaire will take approximately 10 minutes to complete.

The interview is the first phase of this research study. There is a second phase of this research which involves completion of additional questionnaires. If you are interested in this second phase as well, please indicate your interest when you complete your consent form.

WHAT INFORMATION WILL BE KEPT PRIVATE?

Computer files containing the interview files and questionnaire responses will be stored on a secure server hosted by the University of Toronto. Consent forms will be uploaded and stored on the secure server at the University of Toronto (or respective site in the country of participation). Only researchers and advisors directly involved with the study will be able to access these files.

Audio files from the interviews will immediately be transferred from the recording device to a secure, online storage site with password protection. The files on the recorded device will then be deleted. Audio files will be deleted from the online storage site after the study is published, and all paper and electronic files will be destroyed ten years after the study is completed.

The one-on-one interview will take place virtually through Zoom. Any information you provide throughout your participation in the study, including contact information, recordings from the interview and questionnaire responses will be kept strictly confidential and only be made available to the research team and members of the University of Toronto Research Ethics Board who have reviewed the study. No information that would identify you (such as your name) will be recorded on any of our documents. For example, you will be assigned a specific numerical code that will be used to refer to you instead of your name. Only the researchers and investigators will have access to the meaning of this code and it will not be shared with anyone else. We will not include any personal information such as your name that could identify you in any of the publications or presentations related to this study.

Supplemental File 1
Interview Consent Form - Example (Phase 1)

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 in the one-on-one interview personal or uncomfortable to answer. You may choose not to answer questions for any reason and you may stop taking part in the one-on-one interview at any time. Additionally, if you feel you would benefit from having the interview broken up into multiple sessions, this can be arranged with the interviewer. If you become upset during the one-on-one interview or when filling out the questionnaire, the researchers will encourage you to follow up with your health care professional (e.g. physician), qualified counselor, or services at the relevant community site/network, and can provide you with the contact information for support services relevant to your area. Further, the research team will follow up with all participants via email after the interview and will include the contact information for the Principal Investigator / site lead and the relevant community collaborator network should the participant require these services. Choosing to withdraw from the study will not compromise any care you receive through any COVID-19 support networks/services.

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.

WILL I BE PAID TO PARTICIPATE IN THIS STUDY?

You will not be paid to take part in this research study, but you will be given a $30 CAD dollar gift card as a token of appreciation to thank you for your participation in completing the one-on-one interview and questionnaire. If you choose to withdraw from the study during the interview, you will still receive the gift card.

WHAT WILL HAPPEN TO THE INFORMATION FROM THIS STUDY?

The researchers will submit a manuscript for open-access publication as well as communicate the knowledge gained from this study to researchers, health-care providers, community-based organizations and policy makers. Knowledge translation updates will be provided in the form of presentations, slides, fact sheets and social media. This information will also be presented at community organizations and clinics encouraging practical application of the results. Fact sheets of the results will be distributed by email if requested and as handouts. If you are interested in receiving a copy of the fact sheets and publications from the study investigators, you can contact Kelly O'Brien at kelly.obrien@utoronto.ca. All data/publications related to the study will be open access (available to anyone) as a condition of the study's funding in accordance with the joint statement on sharing research data and findings relevant to the novel coronavirus outbreak. Any available data will be in aggregate form, without any personal identifiers to protect the anonymity of participants. A summary of the study results and publications will be openly available on the Long COVID Physio website: https://longcovid.physio.

Date Last Revised: November 5, 2021

Supplemental File 1
Interview Consent Form - Example (Phase 1)

IF I HAVE ANY QUESTIONS OR CONCERNS, WHOM CAN I CONTACT?

If you have any questions about the research study, please contact Kelly O'Brien (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.

Date Last Revised: November 5, 2021

Supplemental File 1
Interview Consent Form - Example (Phase 1)

CONSENT TO PARTICIPATE

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

I have read and understood all of the above. Signing this form does not waive my legal rights or relieve the investigator or sponsors from their legal and professional responsibilities.

I agree and consent to participating in completing the self-reported questionnaire and one-on-one interview.

By signing or giving verbal consent below I am agreeing that:

- I understand the information provided for the above study.
- I have had the opportunity to consider the information, ask questions and have had these questions answered satisfactorily.
- I understand that my participation is voluntary and that I am free to stop the study at any time without punishment.
- I understand that the data collected during the study may be looked at by responsible individuals from the research team, or the regulatory authorities where it is relevant. I give permission to these individuals to have access to the information I provided.
- I agree to participate in the above study.
- For the interview, I agree to be audio recorded.
- I have been provided with a copy of the consent form.

❑ **Provision of written consent**

_____	_____	_____
Participant's Name (please print)	Participant's Signature	Date

❑ **Provision of verbal consent**

_____	_____	_____
Witness' Name (please print)	Witness' Signature	Date

I am willing to be contacted about **future phases of the study** by email or phone.

❑ Yes, Contact: _____
❑ No

Date Last Revised: November 5, 2021

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

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.

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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

Supplemental File 2
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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)
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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

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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 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.

Date Last Revised: November 5, 2021

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!

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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!

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

[After the questionnaires – End Page]

Physical Therapy
UNIVERSITY OF TORONTO

EDQ

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 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.

CIHR IRSC

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

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?
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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)

4

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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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