

Sensibility of the Episodic Disability Questionnaire among adults living with Long COVID in Canada, Ireland, the United Kingdom, and the United States

Julia Nathanson

University of Toronto

Kiera McDuff

University of Toronto

Darren A. Brown

Long COVID Physio

Soo Chan Carusone

McMaster University

Margaret O'Hara

Long Covid Support

Hannah Wei

Patient-Led Research Collaborative

Lisa Avery

University of Toronto

Kristine M. Erlandson

University of Colorado

Ruth Stokes

Long COVID Advocacy Ireland

Liam Townsend

St. James's Hospital

Ciaran Bannan

St. James's Hospital

Susie Goulding

COVID Long Haulers Support Group Canada

Catherine Thomson

Long COVID Physio

Mary Kelly

Long COVID Physio

Sarah O'Connell

Long COVID Advocacy Ireland

Imelda O'Donovan

Long COVID Advocacy Ireland

Angela M. Cheung

University of Toronto

Colm Bergin

St. James's Hospital

Jaime H. Vera

Brighton and Sussex Medical School, University of Sussex

Richard Harding

King's College London

Natalie St. Clair-Sullivan

King's College London

Letícia Soares

Patient-Led Research Collaborative

Lisa McCorkell

Patient-Led Research Collaborative

Nisa Malli

Patient-Led Research Collaborative

Niamh Roche

Long COVID Advocacy Ireland

Jessica Martin

University of Toronto

Kelly K. O'Brien

kelly.obrien@utoronto.ca

University of Toronto

Research Article

Keywords: Patient-reported outcome measures, Long COVID, Episodic Disability, Sensibility

Posted Date: April 14th, 2026

DOI: <https://doi.org/10.21203/rs.3.rs-9261032/v1>

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Additional Declarations: No competing interests reported.

Version of Record: A version of this preprint was published at Journal of Patient-Reported Outcomes on September 19th, 2026. See the published version at <https://doi.org/10.1186/s41687-026-01205-y>.

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ABSTRACT

Background: Persons living with Long COVID experience a range of health-related challenges that may fluctuate over time, known as episodic disability. The Episodic Disability Questionnaire (EDQ) is a 35-item patient-reported outcome measure developed to assess presence, severity and episodic nature of disability across six dimensions: i) physical, ii) cognitive, iii) mental-emotional health, iv) difficulties with day-to-day activities, v) social inclusion, and vi) uncertainty about future health. Our aim was to assess the sensibility of the EDQ among adults living with Long COVID.

Methodology: We conducted a two-phased sensibility assessment of the EDQ. In Phase 1, we assessed the face and content validity of the EDQ by mapping items from the EDQ onto the Episodic Disability Framework, which conceptualizes the health-related challenges living with Long COVID. Using the framework, we developed a 21-item Long COVID EDQ Supplement (LC-EDQ Supplement) for use in conjunction with the EDQ. In Phase 2, we conducted a cross-sectional measurement study involving adults living with Long COVID in Canada, Ireland, United Kingdom, and United States. We electronically administered the EDQ and LC-EDQ Supplement, followed by an 18-item sensibility questionnaire to assess face and content validity, ease of usage and format. Sensibility scores ranged from 1 (highly disagree) to 7 (highly agree). We considered the EDQ and the LC-EDQ Supplement sensible if median sensibility item scores were $\geq 5/7$ for $\geq 80\%$ of items and if none of the items had a median score of $\leq 3/7$.

Results: Of the 798 participants, most identified as female (82%), median age of 47 years (25th,75th percentile: 37, 56), and median of 2 years (1, 3) living with Long COVID. The EDQ and LC-EDQ Supplement met the criterion for sensibility as determined by sensibility item responses $\geq 5/7$ for 16/18 (89%) items on the sensibility questionnaire.

Conclusions: The EDQ and LC-EDQ Supplement demonstrated sensibility among this sample of adults living with Long COVID. Results highlight the EDQ as a practical and feasible tool to assess the multi-dimensional and episodic nature of disability experienced among adults living with Long COVID.

KEYWORDS

Patient-reported outcome measures, Long COVID, Episodic Disability, Sensibility

BACKGROUND

Many individuals are living with persistent symptoms following a SARS-CoV-2 infection, referred to as Long COVID or post-COVID-19 Condition [1]. Authors of a meta-analysis estimated a pooled global prevalence of Long COVID of 36% among individuals with a confirmed COVID-19 diagnosis, with estimates varying across studies and regions [2]. The World Health Organization defined post-COVID-19 Condition as symptoms lasting at least two months that cannot be explained by an alternative diagnosis, typically occurring three months after the onset of a probable or confirmed COVID-19 infection [3]. Commonly reported symptoms of Long COVID include fatigue, breathlessness, post-exertional malaise/ symptom exacerbation (PEM/PESE),

orthostatic intolerance, joint and muscle pain, and cognitive impairment [3–10]. People living with Long COVID reported difficulty returning to work, challenges in their relationships and social participation, problems accessing services, and experiencing stigma, all of which may contribute to disability among those living with the condition [10–26].

Experiences of Episodic Disability in Long COVID

Adults living with Long COVID described the health-related challenges they experience as episodic (fluctuating) and multidimensional in nature [27]. Episodic disability is defined as any physical, cognitive or mental-emotional health symptoms and challenges, difficulties with day-to-day activities, challenges to social inclusion, and uncertainty and worry about the future, all of which may fluctuate over the course of living with Long COVID, daily, or within the course of a day [28]. The Episodic Disability Framework conceptualizes these dimensions of disability, which may be influenced by extrinsic and intrinsic contextual factors, and triggers that can initiate or exacerbate episodes of disability [29]. Measuring episodic disability among people living with Long COVID is important for understanding the health-related challenges in this population. However, to date no patient-reported outcome measure of episodic disability has been assessed for comprehensibility and ease of use in this population.

The Episodic Disability Questionnaire (EDQ)

The Episodic Disability Questionnaire (EDQ) is a patient-reported outcome measure (PROM) developed to assess the presence, severity and episodic nature of disability experienced by persons living with complex chronic conditions [30–32]. The EDQ was derived from the HIV Disability Questionnaire (HDQ) [33–35] and Short-Form HDQ (SF-HDQ) [31], which possess

measurement properties for use with adults living with HIV [29, 34, 36, 36–40]. The conceptual foundation for these measures is the Episodic Disability Framework, originally developed from the perspectives of adults living with HIV [29]. We validated the Episodic Disability Framework, with adults living with Long COVID, which provided a conceptual foundation of the multidimensional and fluctuating nature of disability experienced with Long COVID [27]. Hence, the EDQ has the potential to describe episodic disability experienced by people living with Long COVID.

Utility of the EDQ as a Measure of Episodic Disability in Other Conditions

Measurement properties of the EDQ have been assessed among men and women living with HIV, and with older adults living with complex healthcare needs [30, 32, 41]. The EDQ possesses internal consistency reliability (Cronbach’s alpha: 0.68-0.91), test-retest reliability (intraclass correlation coefficient: 0.64-0.88), construct validity, and precision (minimum detectable change 95% range: 19-25 (for severity)) with adults living with HIV [30]. The EDQ has also been assessed for utility, sensibility (face validity, content validity, ease of usage, and format) [42], and practical applicability to describe the multi-dimensional and episodic nature of disability with older adults with complex health care needs and with persons living with HIV in clinical and community-based settings [32, 37, 41, 43]. Given the fluctuating nature of symptoms of Long COVID, the EDQ may be a valuable tool for measuring and describing disability in this population. Understanding the sensibility of the EDQ among adults living with Long COVID is an important step to advance its potential implementation in future research and clinical settings for this population. However, the properties of the EDQ, such as sensibility (including face and content validity, ease of usage, and format), with persons living with Long COVID are unknown.

Our aim was to assess the sensibility of the Episodic Disability Questionnaire (EDQ) among adults living with Long COVID in Canada, Ireland, United Kingdom and United States.

METHODS

Study Design

We conducted a two-phased sensibility assessment of the EDQ in the context of Long COVID. In Phase 1, members of the team assessed the face and content validity of the EDQ by mapping items from the EDQ onto the Episodic Disability Framework, which conceptualizes the health-related challenges living with Long COVID across the six dimensions of disability [27]. In Phase 2, we conducted a cross-sectional measurement study involving a web-based administration of questionnaires with adults living with Long COVID in Canada, Ireland, United Kingdom (UK), and United States (US) [44]. This study is part of a larger study assessing the measurement properties of the EDQ among adults living with Long COVID in Canada, Ireland, the UK, and the US [44]. In this paper we focus on the sensibility assessment of the EDQ.

Ethics

The Long COVID and Episodic Disability was conducted according to the ethical principles of the Declaration of Helsinki. The study was approved by the XXX at [XXXXXX] (Protocol #XXXXX); and the XXXXXXXX XXXXX (XXX-XXXXX). Informed consent was obtained by all participant in the study.

Patient and Public Involvement

Our research team includes adults living with Long COVID and five community organizations dedicated to Long COVID (COVID Long Haulers Canada [45], Patient-Led Research Collaborative [46], Long Covid Support [47], Long COVID Advocacy Ireland [48], and Long COVID Physio [49]). Adults living with Long COVID were engaged in the conceptualization, design, recruitment, analysis, and knowledge translation of this study. Team members with lived experiences were part of a Core Team that included the Co-Principal Investigators (co-PIs) of the study, clinicians, and researchers, responsible for Phase 1 (mapping items from the EDQ onto the Episodic Disability Framework); and for refinement of data collection tools, participant recruitment, and data analysis for Phase 2 (questionnaire administration). XXXX et al. (2025) described our process of engagement with people with lived experiences in the broader Long COVID and Episodic Disability study [50].

Phase 1 – Sensibility Assessment of the EDQ with the Long COVID Episodic Disability Study

Team – Face and Content Validity

Mapping Episodic Disability Framework to the EDQ

The 35-item EDQ includes six domains: i) physical, ii) cognitive, iii) mental-emotional health challenges, iv) uncertainty, v) difficulties with day-to-day activities, and vi) challenges to social inclusion [30, 31]. We assessed the face and content validity of the EDQ for people living with Long COVID by mapping items of the EDQ onto the Episodic Disability Framework developed in the context of Long COVID [27]. Members of our team (XX, XX, and XX) mapped items of the EDQ onto the Episodic Disability Framework. While all EDQ items mapped onto the Framework, we identified categories in the Framework that were not captured by the EDQ. Hence, we

identified the need to develop a supplement to be used with the EDQ to comprehensively assess disability among adults living with Long COVID [27].

Developing a Long COVID EDQ Supplement

We established a 21-item Long COVID EDQ (LC-EDQ) Supplement to be used in conjunction with the EDQ among adults living with Long COVID to capture the presence, severity, and episodic nature of health challenges living with Long COVID.

Generating the initial list of items: We generated an initial list of items for the LC-EDQ Supplement based on the health challenges from the Episodic Disability Framework that were not captured by the EDQ. Also, we reviewed relevant Long COVID literature and other outcome measures developed for or recommended for use among adults living with Long COVID, to identify potential items for the LC-EDQ Supplement [30, 51, 51–59]. In total, we generated an initial list of 29 potential items.

Item review, prioritization, and refinement: We held one full team and one core team meeting (smaller group of community members with lived experiences (XX, XX, XX, XX, XX, XX, XX, XX), study co-PIs (XX and XX), and research coordinators (XX and XX)) to discuss the inclusion of each proposed item. Our aim was to comprehensively capture health challenges experienced by adults living with Long COVID while avoiding overlap of items with the EDQ, and minimizing respondent burden. We administered a web-based questionnaire to all team members, asking them to independently rank each item by importance on a scale from 1 (least important to include) to 10 (most important to include), using Qualtrics software [60]. We also asked for suggestions for item phrasing to improve clarity and ease of use. Of the 24 team members, 15

(62%) responded. We prioritized the inclusion of items that were in the Episodic Disability Framework. We removed items for which the majority of team members rated the item as $\leq$ 5/10 of importance, to reduce respondent burden. We then reviewed and refined the item phrasing based on team feedback, creating the 21-item LC-EDQ Supplement.

We piloted the final version of the Supplement twice with the team (six of 12 who had lived experiences of Long COVID) to ensure ease of interpretation and feasibility of length of the questionnaire. Some items were re-worded for clarity, and the final version was reviewed by co-PIs (XX and XX).

Phase 2 - Sensibility Assessment of the EDQ with Adults Living with Long COVID – Web-Based Survey

We assessed the sensibility of the EDQ (in conjunction with the LC-EDQ Supplement) using a cross-sectional web-based survey.

Participants and Recruitment

We included adults (18 years of age or older) who self-identified as living with Long COVID, living in Canada, Ireland, the UK, or the US, and who were able to read and understand English.

We recruited individuals from January 11, 2024 to October 15, 2024 from online community-based groups led by community leaders of the study team (COVID Long Haulers Canada [45], Patient-Led Research Collaborative [46], Long Covid Support [47], Long COVID Advocacy Ireland [48], and Long COVID Physio [49]). Our aim was to obtain a sample that was diverse across gender, sex, and country. Community leaders used email and social media to circulate

recruitment materials that included a description of the study and the inclusion criteria. Also, we invited participants from an earlier phase of the study exploring episodic disability who had indicated interest in participating in a future phase of the study [27, 61].

Consent

On the first page of the web-based survey questionnaire, we provided potential participants with details of the rationale and purpose of the study, the inclusion criteria, and possible risks and benefits of participating in the study. This page described the voluntary nature of participation and participants' right to withdraw at any time. Individuals provided written consent by answering "yes" to the following statement: "I agree to participate in this research study".

Data Collection

We administered an online survey questionnaire using Qualtrics web-based software [60] comprised of the EDQ, Long COVID EDQ Supplement, Sensibility Questionnaire, and Demographic questionnaire.

Questionnaires

Episodic Disability Questionnaire (EDQ)

The 35-item EDQ is a generic patient-reported outcome measure of episodic disability [30, 31]. The EDQ includes six domains: i) physical, ii) cognitive, iii) mental-emotional health challenges, iv) uncertainty, v) difficulties with day-to-day activities, and vi) challenges to social inclusion [30, 31]. Participants are asked to rate the extent to which they are living with a health-related

challenge at the time completing the questionnaire on an ordinal scale of 0 (not at all) to 4 (extreme) for 33 items, 0 (not at all) to 2 (very challenging) for 2 items, and 0 (not at all) to 3 (very or extremely) for 1 item [30, 31]. For each item, participants are asked whether the challenge fluctuated in the past week (yes or no) [30, 31]. A final item asks participants to indicate if this is a good or bad day living with their health condition [30, 31].

Long COVID Episodic Disability Questionnaire Supplement (LC-EDQ Supplement)

The LC-EDQ Supplement is a 21-item condition-specific patient-reported outcome measure (PROM) designed to be administered with the EDQ, with the purpose to describe the presence, severity and episodic nature of health challenges experienced among adults living with Long COVID that are not already captured in the EDQ. Each item has a 4-point ordinal scale to capture the severity of each item, and items were dichotomized into present (1-3) or absent (0) to determine the presence score. Similar to the EDQ, for each item respondents are asked whether the health challenge fluctuated in the past week (yes (1) or no (0)), and a final item asks participants to select the statement from the following options that describes how they are feeling that day: “This is a particularly bad day living with Long COVID”, “This is a typical day living with Long COVID”, or “This is a good day living with Long COVID”.

Sensibility Questionnaire

We developed a sensibility questionnaire (**Additional File 1**) based on Feinstein’s criteria for sensibility to assess the sensibility of the EDQ with the LC-EDQ Supplement [31]. The sensibility questionnaire included 18 statements asking about participants’ perspectives on the EDQ and LC-EDQ Supplement [30, 37, 41–43]. Each item was scored on an ordinal scale ranging from 1

(highly disagree) to 7 (highly agree); with 6 items possessing a reversed order of response options 1 (highly agree) to 7 (highly disagree). Statements referred to face validity (6 items), content validity (5 items), format (2 items), ease of usage (3 items), and utility (2 items). Participants were also asked to provide written feedback on the EDQ and LC-EDQ Supplement regarding any items they felt were missing.

Demographic and Health Characteristics Questionnaire

We administered a questionnaire asking about personal and health characteristics [44]. Participants received an electronic gift card in the amount of \$40 CAD equivalent as a token of appreciation for their participation in the study.

Analysis

We used IBM SPSS Statistics to analyze the data [62]. For the demographic and health characteristics questionnaire, we calculated frequencies (%) for categorical variables, and median and 25th and 75th percentiles for continuous variables.

For the sensibility questionnaire, we calculated the median and 25th and 75th percentiles for each item. We determined that the EDQ and LC-EDQ Supplement would be sensible if median scores on the sensibility questionnaire were $\geq 5/7$ for $\geq 80\%$ of the items and if none of the items had a median score of $\leq 3/7$, a threshold used in previous work assessing the sensibility of the HDQ, SF-HDQ, and EDQ among people living with HIV and older adults with complex health needs [34, 37, 41, 43].

RESULTS

228 *Participant Characteristics*

229 A total of 798 participants completed the web-based survey questionnaires between January
230 11, 2024 and August 28, 2025 [63]. The majority of participants lived in Canada (43%) followed
231 by the United Kingdom (23%), the United States (22%), and Ireland (12%). The median age of
232 participants was 47 years (25th, 75th percentile: 37, 56). The majority of participants reported
233 their sex as female (82%), gender as woman (79%) and identified as white (88%). Participants
234 reported a median of 2 years living with Long COVID (25th, 75th percentile: 1,3). See Table 1 for
235 a complete description of participant characteristics.

236 **Table 1: Characteristics of Participants [see end of manuscript]**

237 *Sensibility Questionnaire Results*

238 The EDQ and LC-EDQ Supplement demonstrated sensibility for participants living with Long
239 COVID, as demonstrated by a median item score of $\geq 5/7$ for 16/18 (89%) items, above the
240 threshold of $\geq 80\%$ to meet sensibility criteria [30, 32, 52, 53]. For the 2/18 (11%) items that did
241 not meet the sensibility threshold of $\geq 5/7$ (items 9 and 13), the median score was 4/7. See
242 **Table 2** for the sensibility questionnaire responses.

243 **Table 2: Sensibility Questionnaire Responses**

Item	Sensibility questionnaire item	Median (25th, 75th percentile)	n
1	I was able to answer all questions.	7 (6, 7)	796
2	The instructions were clear and easy to understand.	7 (5, 7)	795
3	The questions were clear and easy to understand.	7 (5, 7)	794
4	Overall, the EDQ and LC-EDQ Supplement make sense.	7 (5, 7)	794

5	The response categories for the questions were adequate.	6 (5, 7)	797
6	The EDQ and LC-EDQ Supplement captured all elements of my disability.	5 (3, 6)	797
7	The EDQ and LC-EDQ Supplement included important questions necessary to describe my disability.	5 (5, 7)	797
8*	The EDQ and LC-EDQ Supplement included repetitive or redundant questions.	5 (4, 6)	793
9*	There were questions missing that should be included.	4 (3, 5)	798
10*	Some of the questions seemed out of order.	5 (4, 6)	792
11	I was able to find my answer in the list of possible answers.	5 (5, 6)	794
12*	The questions made me think about things I preferred not to think about.	5 (4, 6)	793
13	Answering the questions helped me in some way.	4 (3, 5)	794
14*	The EDQ and LC-EDQ Supplement took too long to complete.	5 (5, 7)	797
15*	The EDQ and LC-EDQ Supplement required too much effort to complete.	5 (5, 7)	793
16	The EDQ and LC-EDQ Supplement was easy to complete.	5 (5, 6)	792
17	I would like to receive a summary of my scores after completion.	5 (5, 7)	796
18	Overall, the EDQ and LC-EDQ Supplement are useful for describing disability in Long COVID.	5 (5, 6)	796

244 *Indicates item was reverse-scored

245 Thirty-four percent (n=270) of participants provided additional information on items they felt
246 were missing. These included physical symptoms (including impacts on hair and skin, teeth and
247 dental health), cognitive health challenges (impaired reading ability), mental and emotional
248 health challenges (irritability; feelings of worthlessness and hopelessness; suicidal ideation),
249 challenges to social inclusion (ability to tolerate the presence of others; loss of personal
250 relationships), and difficulty with day-to-day activities (eating; self-care). Some participants

suggested adding items that pertain to living strategies (behaviors or beliefs adopted to avoid or mitigate disability), and extrinsic factors (experiences in the healthcare system, participation in Long COVID research, and stigma). Other responses suggested more detailed descriptions of items included in the EDQ or LC-EDQ, and suggestions for formatting. See **Additional File 2** for an overview of additional suggested items from participants.

DISCUSSION

The overall aim of the study was to assess the sensibility of the EDQ in a sample of adults living with Long COVID in Canada, Ireland, the UK, and the US. We found that the EDQ possessed face validity using categories in the Episodic Disability Framework that was derived from the perspectives of adults living with Long COVID. However, not all aspects of experiences of disability among adults living with Long COVID were captured by the EDQ resulting in the development of the LC-EDQ Supplement to be used in conjunction with the EDQ. Results from the sensibility questionnaire indicated that the EDQ and LC-EDQ Supplement together possessed sensibility for use with adults living with Long COVID, demonstrated by achieving the threshold of sensibility (scores of $\geq 5/7$ for $\geq 80\%$ of the items), with 16 of the 18 items (89%) receiving scores of $\geq 5/7$.

Two items did not achieve the threshold of $\geq 5/7$ on the sensibility questionnaire. Item 9 “There were questions missing in the EDQ and LC-EDQ Supplement that should be included” may not have reached the threshold due to the large variance in reported symptoms of Long COVID [4]. Items suggested by participants primarily included other symptoms of Long COVID, most of which fit within the six dimensions (domains) of disability included in the EDQ. These findings

emphasize the numerous symptoms associated with Long COVID and the heterogeneous nature of health challenges experienced among persons living with Long COVID [4, 64]. We limited the LC-EDQ Supplement to 21 items to mitigate respondent burden. Interestingly, items in the LC-EDQ Supplement were included in the earlier long-version (69-items) of the HIV Disability Questionnaire. The HDQ was shortened to the EDQ using Rasch analysis (a method for developing PROMs and reducing items) to enhance its feasibility for use in clinical and community settings [31, 65–68]. This aligns with other PROM development in the context of Long COVID, where the list of symptoms captured were reduced from a larger initial pool to enhance utility [59, 69]. Future research may implement Rasch analysis to evaluate the items of the EDQ and LC-EDQ Supplement together among people living with Long COVID. Overall, findings highlight the complexity of Long COVID, and challenges of capturing all possible symptoms experienced among persons living with Long COVID in one PROM [70]. Some participants additionally suggested adding items related to extrinsic factors and living strategies. As per the Episodic Disability Framework, these are contextual factors that influence dimensions of disability, but are beyond the scope and purpose of the EDQ [27]. These findings highlight the importance of administering outcome measures that assess stigma, experiences in the healthcare system, and living strategies to comprehensively enhance our understanding of the experiences of adults living with Long COVID. Our results emphasize the challenges of capturing the complex and multidimensional health-related challenges in one questionnaire and the considerations of balancing comprehensibility with feasibility when assessing disability in the context of Long COVID [4, 70, 71].

Item 13, “I felt that answering the questions helped me in some way”, may not have achieved the sensibility threshold score for various reasons. It is possible that participants found that while the questionnaire captured their experiences, it did not provide any intervention to mitigate their health challenges. Completing outcome measures can help respondents conceptualize, describe, or articulate their health challenges experienced living with a condition [72–74]. In a past assessment of the EDQ with older adults living with complex health needs, participants reported that completing the EDQ could help them engage in a discussion with their health provider about their health challenges [41]. In that study, the EDQ met sensibility criteria with participants rating sensibility of the EDQ ($\geq 5/7$ on the sensibility questionnaire), for all items of the questionnaire [41]. However, the study involved administering the EDQ in person and recruiting participants through a family health team, meaning they were connected with providers with whom they could potentially discuss their EDQ results. This might indicate that perceived sensibility of the EDQ could be enhanced for persons who are connected to care and could share their results with providers, or that completing the EDQ in-person could lead to better perceived sensibility. In the current study, it is possible that the mode of electronic administration influenced perceptions of EDQ utility, suggesting potential for use in remote (online) forms of clinical care. Furthermore, people living with Long COVID have reported difficulty accessing care, which may have influenced their responses if they did not have access to health providers to discuss their EDQ scores [18–23, 75, 76]. This highlights the importance of the introduction to the EDQ, clearly indicating the purpose of the outcome measure – to describe presence, severity and episodic nature of disability living with Long COVID.

Strengths of our study include our international, community-engaged approach [50] and multi-method approach to assessing sensibility. We used a sensibility questionnaire previously developed to assess properties of the EDQ [34, 37, 41, 43]. We used lessons learned from previous research in the field of episodic disability and rehabilitation to develop a strong foundation for this community-academic-clinical collaboration [77]. Limitations included our assessment of sensibility for both the EDQ and LC-EDQ Supplement, hence we cannot ascertain whether the EDQ alone possessed sensibility. We developed the LC-EDQ Supplement for the purposes of this study based on the findings from Phase 1. The LC-EDQ Supplement does not possess a formal scoring structure (compared to the EDQ, which is an established patient-reported outcome measure). Future work should examine the domain structure and measurement properties of the EDQ and LC-EDQ Supplement in greater detail in the context of Long COVID.

CONCLUSION

The EDQ and LC-EDQ Supplement together demonstrated sensibility for use with adults living with Long COVID. Clinicians, researchers and persons living with Long COVID should use the EDQ in combination with patient-reported outcome measures to capture the experiences of disability and contextual factors among adults living with Long COVID. Future directions include further assessment of the measurement properties of the EDQ among people living with Long COVID.

LIST OF ABBREVIATIONS

EDQ: Episodic Disability Questionnaire

335 LC-EDQ: Long COVID Supplement - Episodic Disability Questionnaire

336 PEM: Post-exertional malaise

337 PESE: Post-exertional symptom exacerbation

338 PROM: Patient-reported outcome measure

339 HIV: Human immunodeficiency virus

340 HDQ: HIV Disability Questionnaire

341 SF-HDQ: Short-Form HIV Disability Questionnaire

342 **DECLARATIONS**

343 **Ethics approval and Consent to Participate:** The study was approved by the XXXXX at XXXXX
344 (Protocol #XXXX); and the XXXX (XXX-XXX-XXXX).

345 Participants provided written consent by answering “yes” to the following statement: “I agree
346 to participate in this research study” on the survey questionnaire.

347 **Consent for publication**

348 Not applicable

349 **Competing interests**

350 Removed for anonymization.

351 **Funding**

352 This work is supported by the XXX (Funding Research Number #: XXXX), XXXX). XXX is supported
353 by a XXXXX (XXX) and XXX is supported by a XXX.

354 **Authors' Contributions**

355 Removed for anonymization.

356 **Acknowledgements**

357 Removed for anonymization.

358 **ADDITIONAL FILES**

359 Additional File 1 (PDF): Sensibility Questionnaire

360 Additional File 2 (PDF): Sensibility Questionnaire Responses to Question Pertaining to Missing
361 Items.

362

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595 **Table 1: Characteristics of Participants**

Characteristic (n=798)	N (%)
Age (in years)	
Median (25 th , 75 th percentile)	47 (37, 56)
Mean (Standard Deviation)	47 (11)
Min-max	18-84
Sex	
Female	657 (82%)
Male	137 (17%)
Intersex	1 (<1%)
Other	3 (<1%)
Gender	
Woman	631 (79%)
Man	134 (17%)
Non-binary	17 (2%)
Other ¹	12 (1%)
Country of residence	
Canada	344 (43%)
United Kingdom	182 (23%)
United States	172 (22%)
Ireland	98 (12%)
Ethnic group and/or race (n=791)	
White	694 (88%)
Mixed or multiple ethnic groups	23 (3%)
Black, Black British, Caribbean, African, or African American	19 (2%)
Asian, South Asian, or South East Asian	17 (2%)
First Nations, Indigenous, Metis, or Native American	16 (2%)
Hispanic or Latino/a/x	5 (1%)
Arab, Middle Eastern, or North African	2 (<1%)
Native Hawaiian or Pacific Islander	2 (<1%)
Other ethnicity/race ²	13 (2%)
Marital or Partnership Status	
Married	404 (51%)
Single (never married, never in a civil partnership)	197 (25%)
Divorced	90 (11%)
In a registered civil partnership	30 (4%)
Separated, but still legally married	26 (3%)
Widowed	17 (2%)
Formerly in a civil partnership (now dissolved or surviving partner)	7 (1%)
Prefer not to answer	20 (3%)
Have Children	485 (62%)
Employment status (n=788)	

Characteristic (n=798)	N (%)
Full-time (≥ 30 hours/week)	197 (25%)
Part-time (≤ 30 hours/week)	118 (15%)
Volunteering	9 (1%)
Student	14 (2%)
Retired	69 (9%)
Retired (earning part-time income)	15 (2%)
On disability	211 (27%)
Unemployed seeking work	25 (3%)
Unemployed not seeking work	77 (10%)
Other ³	53 (7%)
Number of years living with Long COVID	
Median (25th, 75th percentile)	2 (1,3)
Mean (Standard Deviation)	2 (1)
Min-max	0-4

Legend: ¹Other responses included: *gender non-conforming, agender, gender queer, non-binary, trans man, trans woman*; ²Other responses included: *Greek, Irish, Jewish, Mediterranean, Mauritian, Northern European, Portuguese*; ³Other responses included: *on career break, employed but unable to work, on short-term leave, awaiting disability, and full-time carer/parent*.

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