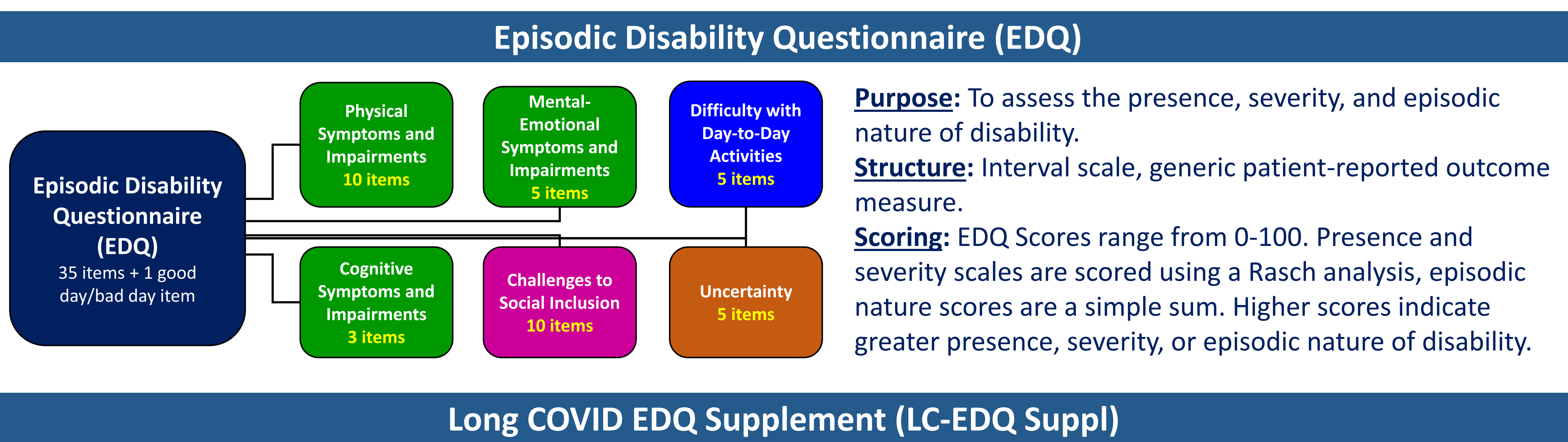


**Background:** Many people are living with persistent and prolonged symptoms following COVID-19 infection, known as Long COVID.

- Several symptoms have been reported, which pose complex challenges with working, daily activities, and overall health.
- Measuring disability in Long COVID is important for understanding the experiences, challenges, and needs of patients.
- The Episodic Disability Questionnaire (EDQ)** was developed for people living with HIV, and captures multi-dimensional and fluctuating health challenges. **The properties of the EDQ are unknown in the context of Long COVID.**
- A Long COVID EDQ Supplement (LC-EDQ Suppl) was developed by members of the team for use with the EDQ to capture elements of disability in Long COVID not captured by the EDQ.

## Purpose

To assess the sensibility of the EDQ and LC-EDQ Suppl among adults living with Long COVID in Canada, Ireland, the United Kingdom (UK), and United States (US).



## Long COVID EDQ Supplement (LC-EDQ Suppl)

**Purpose:** To be used with the EDQ to describe disability experienced by adults living with Long COVID.

**Structure:** 21 questions meant to be used in combination with the EDQ. There is no total score for the LC-EDQ Suppl.

**Development:** Developed by members of this team, including persons with lived experiences, and representatives from Long COVID support groups. Questions are based on interviews with 40 adults living with Long COVID, then refined and piloted by members of the study team.

## Methods

**Study Design:** Survey.

**Community Engagement:** Expertise in measure development, refinement, study recruitment, and interpretation of findings.

**Participants & Recruitment:**

- Adults (≥18 years) living with Long COVID in Canada, Ireland, the UK, and the US.
- Recruitment online via **COVID Long-Haulers Canada**, **Long COVID Advocacy Ireland**, **Long COVID Physio**, **Long COVID Support**, and **Patient-Led Research Collaborative**.

**Data Collection:** A four-part web-based survey administered via Qualtrics from January 2024 to October 2025: **1) EDQ; 2) LC-EDQ Suppl; 3) Sensibility questionnaire** (18 items) assessing the face and content validity, ease of use, and format of these measures; and **4) Demographic questionnaire**.

**Analysis:** Sensibility scores ranged from 1 (highly disagree) to 7 (highly agree). We considered the EDQ and LC-EDQ Suppl sensible if median sensibility scores were ≥5/7 (7-point Likert scale) for ≥80% (15/18) of the items. Six items were reverse-scored.

## Results

Characteristics of Participants (n=798)	Sensibility Questionnaire Findings (n=798)																																																																																										
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Sensibility scores of ≥5/7 were achieved for 16/18 (89%) of items on the sensibility questionnaire. Items indicated with an asterisk (\*) were reverse-scored, such that higher scores indicated greater sensibility. **EDQ and LC-EDQ Suppl demonstrated sensibility in this sample of adults living with Long COVID.**

	Presence Median (25 <sup>th</sup> , 75 <sup>th</sup> percentile)	Severity Median (25 <sup>th</sup> , 75 <sup>th</sup> percentile)	Episodic Median (25 <sup>th</sup> , 75 <sup>th</sup> percentile)
<b>Domain</b>			
<b>Physical</b>	75 (66, 100)	49 (43, 55)	60 (30, 80)
<b>Cognitive</b>	100 (100, 100)	48 (42, 61)	33 (0, 100)
<b>Mental-Emotional</b>	100 (77, 100)	51 (41, 61)	40 (0, 80)
<b>Uncertainty</b>	100 (78, 100)	55 (45, 65)	0 (0, 40)
<b>Day-to-day Activity</b>	100 (78, 100)	45 (38, 54)	20 (0, 60)
<b>Social Inclusion</b>	67 (55, 82)	47 (41, 53)	0 (0, 29)

**Acknowledgement:** Canadian Institutes of Health Research - Operating Grant: Emerging COVID-19 Research Gaps and Priorities Funding Opportunity (FRN: GA4 – 177753)



## Discussion

- EDQ and LC-EDQ Suppl possess sensibility (face and content validity, ease of use, format) for use among this sample of adults living with Long COVID in Canada, Ireland, the UK, and the US.
- Implications for Clinical Practice:** Clinicians and researchers can use findings to inform approaches to disability measurement among adults living Long COVID.
- Strengths & Limitations:** Strengths included our community engaged approach, and international scope of study. Limitations include diversity of sample, and methodological challenges with a web-based survey study design.
- Future Research:** Further property assessment is needed in the context of Long COVID, including assessing construct validity and reliability.