

**Additional File 2- Sensibility of the Episodic Disability Questionnaire among adults living with Long COVID in Canada, Ireland, the United Kingdom, and the United States**

**Sensibility Questionnaire Responses to Question Pertaining to Missing Items**

As part of the sensibility questionnaire, we asked participants the following: “You indicated that there were questions missing from the EDQ and LC-EDQ Supplement. Please describe what questions were missing.” We received 270 responses to this item on the sensibility questionnaire. Several participant responses included specific health challenges and symptoms that could be addressed by the EDQ and LC-EDQ Supplement. Some responses suggested elaborations or different wording for concepts that were covered by the EDQ and LC-EDQ Supplement. Other responses related more to living strategies and extrinsic factors, which go beyond the scope of the EDQ. Finally, some other responses included feedback on the format of the questionnaire.

**Symptoms or health challenges that were missing**

Some participants indicated that they have many additional symptoms that were not addressed by the EDQ or LC-EDQ Supplement. Table 1 organizes these symptoms and health challenges by domain of the EDQ. Some of these health challenges were discussed in the development of the supplement, and were removed to pare down the length of the supplement to make it more feasible for administration and completion.

**Table 1: Feedback on Missing Items by Domain of EDQ**

<b>Domain</b>	<b>Symptom or Health Challenge</b>
Physiological	Immune functioning
Physical Symptoms and Impairments	Impacts on skin, hair, skin irritation
	Fatigue, extreme fatigue, inability to stay awake
	Impacts on teeth and dental health
	Impaired hearing
	Incontinence and or bowel/urinary issues
	Inflammation
	Internal vibrations
	Loss of taste and smell
	Permanent health changes, organ damage
	Sinus congestion
	Tinnitus
	Tremors
Cognitive Symptoms and Impairments	Weight fluctuation
	Ability to read
Mental and Emotional Health Challenges	Suicidal ideation
	Feelings of worthlessness, hopelessness
	Sense of autonomy, lack of independence
	Irritability
	Feeling forgotten by society and government
	Depersonalization, paranoid thoughts, derealization
	Fear, fear of death from symptoms
Panic	
Uncertainty or Worry about the Future	N/A

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<b>Domain</b>	<b>Symptom or Health Challenge</b>
Difficulties with Day-to-Day Activities	Eating /appetite
	Hours needed to sleep during the day, amount of rest needed during the day, average number of hours of energy in the day
	Changes in activities (e.g. Avoiding or changing routine activities to avoid PESE)
	Inability to drive and the impacts of the inability/limited ability to drive
	Difficulty with self-care
Challenges to Social Inclusion	Ability to tolerate movement/presence of others
	Impacts on interpersonal relationships, loss of relationships

**More detail or elaboration of specific symptoms or health challenges**

Some participants provided feedback on symptoms or health challenges that may have been addressed in some capacity in the EDQ or LC-EDQ Supplement, but where they “felt like the questions didn’t do justice describing the symptoms.” These responses often included more detailed descriptions or alternate wording to the items included in the EDQ and LC-EDQ Supplement, but broadly represented the same concepts.

**Living strategies and extrinsic factors**

In addition to symptoms that participants felt the EDQ and LC-EDQ Supplement did not capture sufficiently, some participants described other aspects of their experiences living with Long COVID that they did not feel were addressed by the questionnaires. For example, participants described living strategies (behaviours or beliefs that they adopt or avoid to mitigate their disability) that they identified as important to them that were not addressed by the EDQ or LC-EDQ Supplement. Participants also described extrinsic factors that influenced their disability that they felt were not adequately captured by the EDQ or LC-EDQ Supplement, such as stigma and experiences in the medical system.

**Overall feedback and format**

Some participants described suggestions for the overall format of the EDQ and LC-EDQ Supplement, including feedback on the one-week timeframe of the questionnaire potentially being insufficient to capture their fluctuations in health challenges or symptoms, and the difficulty of establishing an appropriate comparator for symptoms. Other feedback suggested that the questionnaire could also capture the intensity of the fluctuation of symptoms, and that an opportunity to elaborate on their symptoms in their own words would be useful. Participants also suggested separating the response option ‘Not applicable’ from the response option ‘Not at all’.