Supplemental File 2 – Demographic Questionnaire
Conceptualising the Episodic Nature of Disability among Adults Living With Long COVID: A Qualitative Study

Supplemental File 2 - Long COVID Participant Demographic Questionnaire
Episodic Disability and Long COVID Study

Participant ID:_____ **Date : _____**

The following questions pertain to your background, characteristics, and health. Please complete the following questions below to the best of your ability.

1) What country to you live in?
- ☐ Canada
- ☐ United States
- ☐ Ireland
- ☐ United Kingdom

2) What county/region/province/state do you live in?

2) What was the community organization through which you found out about the study?
- ☐ Long Haulers Support Group in Canada
- ☐ Patient-Led Research Collaborative
- ☐ Long COVID Physio
- ☐ Long COVID Support
- ☐ Long COVID Ireland

3) What is your **age**? (in years): _____

4) What is your **sex**? (a question about gender identity will follow)
- ☐ Female
- ☐ Male
- ☐ Intersex
- ☐ Other – Please Describe: _____

5) Is the gender you identify with the same as your sex registered at birth?
- ☐ Yes
- ☐ No

6) What is the **gender** you identify with?
- ☐ Man
- ☐ Woman
- ☐ Trans-Man
- ☐ Trans-Woman
- ☐ Non-Binary
- ☐ Gender Non-Conforming
- ☐ Two-Spirited
- ☐ Other – Please describe: _____

O'Brien KK, *et al. BMJ Global Health* 2023; 8:e011276. doi: 10.1136/bmjgh-2022-011276

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7) How would you describe your **national identity**?
- ☐ British
- ☐ English
- ☐ Welsh
- ☐ Scottish
- ☐ Northern Irish
- ☐ Irish
- ☐ American
- ☐ Canadian
- ☐ Other – Please describe: _____

8) How would you describe your **ethnic group and/or race**?
- ☐ Arab, Middle Eastern or North African
- ☐ Asian, South Asian, or South East Asian
- ☐ Black, Black British, Caribbean, African, or African American
- ☐ First Nations, Native American, or Indigenous
- ☐ Hispanic or Latino/a/x
- ☐ Mixed or Multiple ethnic groups – Please describe: _____
- ☐ Native Hawaiian or other Pacific Islander
- ☐ White
- ☐ Other ethnicity/race – Please describe: _____

9) Which of the following best describes your **sexual orientation** or sexuality?
- ☐ Straight or Heterosexual
- ☐ Gay
- ☐ Lesbian
- ☐ Bisexual
- ☐ Asexual
- ☐ Pansexual
- ☐ Other sexual orientation – Please describe: _____

10) What is your current **marital or partnership status**? *Please check only one box.*
- ☐ Single, that is, never married and never registered in a civil partnership
- ☐ Married
- ☐ Separated, but still legally married
- ☐ Divorced
- ☐ Widowed
- ☐ In a registered civil partnership
- ☐ Separated, but still legally in a civil partnership
- ☐ Formerly in a civil partnership which is now legally dissolved
- ☐ Surviving partner from a civil partnership
- ☐ Prefer not to answer

11) Do you have any **children**?
- ☐ Yes
- ☐ No

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12a) Do you **live alone** (or alone with pets)?
- ☐ Yes
- ☐ No

12b) Please describe who you **currently live with?** Check 'Yes' or 'No' for each of the following:

	Yes	No
a) I live with my child/children (dependent)	☐	☐
b) I live with my adult child/children	☐	☐
c) I live with my partner or spouse	☐	☐
d) I live with my siblings	☐	☐
e) I live with my parents	☐	☐
f) I live with my extended family	☐	☐
g) I live with unrelated people (e.g. with friends or roommates)	☐	☐

13) What is your current **employment status**? *Please check one that best describes your employment status.*
- ❑ Full-time employment (30 hours or more per week)
- ❑ Part-time employment (less than 30 hours per week)
- ❑ Volunteering (working without pay)
- ❑ Student (either part-time or full-time)
- ❑ Retired
- ❑ I am retired but also earning some part-time income
- ❑ On disability
- ❑ Unemployed / not working, but seeking work
- ❑ Unemployed / not working, not seeking work
- ❑ Other – Please describe ____

14) Has your **employment changed** since living with **Long COVID**?
- ☐ No, unchanged employment status
- ☐ Yes, I now work reduced or altered hours due to Long COVID
- ☐ Yes, I changed my employment role or job due to Long COVID
- ☐ Yes, I am unable to work/on a leave of absence from work due to Long COVID
- ☐ Yes, I lost my job or I am now unemployed due to Long COVID
- ☐ Yes, my employment status has changed but not directly due to Long COVID

15) What is the main source of your **personal income**?
- ☐ Full-time Employment
- ☐ Part-time Employment
- ☐ Self-Employment
- ☐ Disability (e.g Disability Living Allowance, Severe Disablement Allowance, Incapacity Benefit etc.)
- ☐ Social Security / Social Welfare / Benefits
- ☐ Worker's Compensation
- ☐ Employment Insurance / Long-Term Disability
- ☐ Retirement Pension
- ☐ Basic State Pension/State Second Pension (S2P)
- ☐ Informal street-related work (such as pan handling)
- ☐ Under the table work
- ☐ Student loans
- ☐ Other – Please specify: _____

16) What is the highest level of **education** you have completed? *Please check only one box.*

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- ❑ No formal education
- ❑ Completed secondary / high school
- ❑ Completed trade or technical training (received certification / diploma)
- ❑ Completed college (received degree or diploma)
- ❑ Completed university (received degree)
- ❑ Post-graduate education

17) Do you look after, or **give any help or support** to, a dependent child/children, someone living with a long-term physical or mental health conditions or illnesses, or someone with problems related to old age? *Please check only one box.*

- ☐ No
- ☐ Yes, 9 hours a week or less
- ☐ Yes, 10 to 19 hours a week
- ☐ Yes, 20 to 34 hours a week
- ☐ Yes, 35 to 49 hours a week
- ☐ Yes, 50 or more hours a week

18a) Do you **receive any help or support** because of long-term physical or mental health conditions or illnesses, or problems related to age? *Please check only one box.*

- ☐ No
- ☐ Yes, 9 hours a week or less
- ☐ Yes, 10 to 19 hours a week
- ☐ Yes, 20 to 34 hours a week
- ☐ Yes, 35 to 49 hours a week
- ☐ Yes, 50 or more hours a week

18b) (*Conditional Question*) Is the **help or support** you receive new because of Long COVID?

- ☐ Yes
- ☐ No

19a) What is your current COVID-19 **vaccination status**?

- ☐ Not vaccinated
- ☐ Partially vaccinated (i.e., 1 dose received)
- ☐ Fully vaccinated without a booster dose (i.e., 2 doses received or 1 dose of Janssen/Johnson & Johnson)
- ☐ Fully vaccinated with a booster dose (i.e., 3 doses received or 2 doses of Janssen/Johnson & Johnson)

19b) (*Conditional Question*) What was the **last vaccine** you received?

- ☐ Pfizer-BioNTech
- ☐ Moderna
- ☐ AstraZeneca/COVISHIELD
- ☐ Janssen (Johnson & Johnson)
- ☐ Other

19c) (*Conditional Question*) What was the date of your most recent vaccine (DD/MM/YY)? _____

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20) Listed below are some **symptoms** that individuals may experience when living with Long COVID. For each one, check **'Yes, Have Experience Since COVID-19'** if you have ever experienced the symptom since having COVID-19, **'Yes, Also Living with Before COVID-19'** if you experienced the symptom prior to having COVID-19, and **'No'** if you have not experienced the symptoms. We are interested in knowing if you have experienced these symptoms now and before, even if they have improved, resolved, or been managed with medications or other treatments.

Symptoms	**Yes, Have Experienced Since COVID-19**	**Yes, Also Living with Before COVID-19**	**No**
Fatigue or Exhaustion	☐	☐	☐
Post-Exertional Symptom Exacerbation or Post-Exertional Malaise (PEM) *	☐	☐	☐
Shortness of breath (dyspnea) or increased respiratory effort	☐	☐	☐
Difficulty thinking or concentrating (also known as Brain Fog)	☐	☐	☐
Cough	☐	☐	☐
Chest tightness or pain	☐	☐	☐
Headache	☐	☐	☐
Palpitations and/or high heart rate (tachycardia)	☐	☐	☐
Painful joints (athralgia)	☐	☐	☐
Painful muscles (myalgia)	☐	☐	☐
Numbness or loss of sensation (paresthesia)	☐	☐	☐
Abdominal pain	☐	☐	☐
Feeling sick (nausea)	☐	☐	☐
Diarrhea	☐	☐	☐
Reduced appetite (anorexia)	☐	☐	☐
Increased appetite			
Sleep difficulties (insomnia)	☐	☐	☐
Fever	☐	☐	☐
Lightheadedness (pre-syncope)	☐	☐	☐
Fainting (syncope)	☐	☐	☐
Dizziness	☐	☐	☐
Pain	☐	☐	☐
Skin rashes	☐	☐	☐
Circulation changes such as cold hands or feet	☐	☐	☐
Sensation changes such as pins and needles in the hands, feet, arms and/or legs	☐	☐	☐
Neurological changes such as problems moving limbs, joints or muscles	☐	☐	☐
Mood changes	☐	☐	☐
Taste and smell changes (dysgeusia and anosmia)	☐	☐	☐
Menstrual cycle irregularities	☐	☐	☐
Bowel and bladder control changes			
Erectile dysfunction including pain with erections or change to shape of the penis (Peyronies)	☐	☐	☐

* Post-Exertional Symptom Exacerbation is the worsening of symptoms following even minor physical, mental, or social exertion, with symptoms typically worsening for 12 to 48 hours after activity and lasting days or even weeks.

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21) Listed below are some **health conditions** that individuals may live with in addition to Long COVID. For each one, check **'Yes, Now**' if you are currently living with the condition, **'Yes, Also Living with Before COVID-19'** if you lived with the condition prior to having COVID-19, and **'No'** if you do not live with the condition. We are interested in knowing if you are living with these conditions, even if you are managing them with medications.

Health Conditions	**Yes, Now**	**Yes, Also Living with Before COVID-19**	**No**
a) Addiction or Substance Use Disorder (e.g. alcohol, drugs,)	☐	☐	☐
b) Anemia (Low red blood cells or hemoglobin in your blood)	☐	☐	☐
c) Auto-immune disease such as systemic lupus, auto-immune hepatitis, multiple sclerosis, or rheumatoid arthritis (typically requiring immune suppressive medications for treatment)	☐	☐	☐
d) Cancer, Please specify: _____	☐	☐	☐
e) Cardiovascular disease (e.g. coronary artery disease, heart attack, angina, stroke, arrhythmia (irregular heart beat)	☐	☐	☐
f) Persistent Pain – Joint (e.g. arthritis)	☐	☐	☐
g) Persistent Pain – Neuropathic (e.g. peripheral neuropathy or sensation changes in the hands, feet, arms and/or legs)	☐	☐	☐
h) Persistent Pain – Soft Tissue (muscle pain)	☐	☐	☐
i) Cognitive decline (e.g. memory loss, confusion, trouble thinking clearly or solving day-to-day problems)	☐	☐	☐
j) Diabetes	☐	☐	☐
k) Eye disorder (e.g. glaucoma, macular degeneration)	☐	☐	☐
l) Fibromyalgia	☐	☐	☐
m) Gastrointestinal Conditions (e.g. stomach ulcers, irritable bowel syndrome, diarrhea, constipation, severe heart burn)	☐	☐	☐
n) Hearing difficulty (have or need hearing aid(s))	☐	☐	☐
o) HIV	☐	☐	☐
p) Hepatitis B co-infection	☐	☐	☐
q) Hepatitis C co-infection	☐	☐	☐
a. If no to p), were you living with Hepatitis C in the past and treated?	☐	☐	☐
r) High blood pressure	☐	☐	☐
s) High Cholesterol (elevated levels of cholesterol in the blood(hypercholesterolemia)	☐	☐	☐
t) History of an organ transplant	☐	☐	☐
u) HPV (human papillomavirus; e.g., genital warts, or found on abnormal pap smears)	☐	☐	☐
v) Kidney disease	☐	☐	☐
w) Liver disease	☐	☐	☐
x) Lung Disease (such as Chronic Obstructive Pulmonary Disease (COPD). Asthma, chronic bronchitis, emphysema)	☐	☐	☐
y) Mental health condition (e.g. depression, anxiety)	☐	☐	☐
z) Obesity (when excess body fat has accumulated to the extent that it has adverse effects on your health; or when body mass index (which compares weight and height) is greater than 30kg/m^2)	☐	☐	☐

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aa) Osteoarthritis (e.g. joint disease caused by loss of joint cartilage)	☐	☐	☐
bb) Osteopenia or osteoporosis (e.g. decreased bone density)	☐	☐	☐
cc) Parkinson's Disease (or Parkinsonism)	☐	☐	☐
cc) Peripheral artery disease	☐	☐	☐
dd) Problems urinating (incontinence or prostate enlargement)	☐	☐	☐
ee) Trouble sleeping (insomnia)	☐	☐	☐
ff) Obstructive sleep apnea			
gg) Other, Please describe _____	☐	☐	☐

Health and COVID Specific Questions

The following questions pertain to your general health and living with Long COVID.

22) Do you have any **physical or mental health conditions** or illnesses lasting or expected to last 12 months or more?

☐ Yes
☐ No

23) Do any of your conditions or illnesses **reduce your ability to carry out day-to-day-activities** (e.g., getting dressed, preparing and eating meals, carrying out household tasks, shopping, interacting with family or colleagues, etc.)? *Please check only one box.*

☐ Yes, a lot
☐ Yes, a little
☐ Not at all

24) How is **your health in general now**? *Please check only one box.*

☐ Very good
☐ Good
☐ Fair
☐ Bad
☐ Very bad

25) **Compared to one year ago**, how would you rate your health in general now? *Please check only one box.*

☐ Much better now than one year ago
☐ Somewhat better now than one year ago
☐ About the same as one year ago
☐ Somewhat worse than one year ago
☐ Much worse than one year ago

26) **When did you first develop symptoms of acute COVID-19** or symptoms consistent with the SARS-CoV-2 virus? (Recorded as month and year eg: March 2020):

Month: _____ Year: _____

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27) During the initial period of COVID-19, **how were your symptoms managed**? *Check all that apply.*

- ☐ I remained at home and received no healthcare support
- ☐ I remained at home and was supported by a General Practitioner (GP) or Primary Care Provider
- ☐ I remained at home and was supported by other healthcare support
- ☐ I was admitted to hospital
- ☐ I was admitted to critical or intensive care

28a) Have you been **tested for COVID-19** and received a **positive test result**?

- ☐ No, I have not been tested
- ☐ No, I have been tested and my results were negative (eg: COVID-19 not detected)
- ☐ Yes, positive PCR test (eg: swab test)
- ☐ Yes, positive antigen test (eg: rapid test)
- ☐ Yes, positive antibody test (eg: blood test)

28b) (*Conditional Question*) Has not being tested or not having a positive test result affected your access to any Long COVID services or support?

- ☐ No
- ☐ Yes – Please describe: _____

29) **How long** have you been living with **Long COVID**? years: _____months: _____

30a) Have you experienced **relapses** in your symptoms?

- ☐ Yes
- ☐ No

30b) (*Conditional Question*) What were the **triggers** of your relapses?

- ☐ Physical exertion such as daily activities performed in day-to-day life
- ☐ Exercise such as sports, running, swimming or other activities to improve health and fitness
- ☐ Mental or cognitive exertion such as online meetings, work, reading, or watching TV
- ☐ Social exertion such as being around family, friends, or work colleagues
- ☐ Stress
- ☐ Menstruation
- ☐ Alcohol
- ☐ Caffeine
- ☐ Weather conditions (i.e., heat)
- ☐ Employment responsibilities
- ☐ Home, household, or family responsibilities
- ☐ Other triggers – Please describe _____