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Living with post COVID-19 symptoms: A survey of people's experiences

Submission date
22/10/2024

Recruitment status
No longer recruiting

Registration date
23/10/2024

Overall study status
Completed

Last Edited
28/02/2025

Condition category
Other

[X] Prospectively registered
[_] Protocol
[_] Statistical analysis plan
[_] Results
[_] Individual participant data
[X] Record updated in last year

Plain English summary of protocol
Background and study aims
Post COVID-19 condition (PCC), also known as Long Covid, occurs when people continue to experience symptoms for at least two months after the initial COVID-19 infection. These symptoms can affect multiple parts of the body and significantly impact quality of life. Over 200 different symptoms have been reported, including fluctuating health, changes in self-identity, and difficulties accessing healthcare. Many patients feel dismissed by healthcare professionals, which adds to their struggles. New tools like natural language processing and speech-based surveys are being used to better understand the experiences of those living with PCC, aiming to improve patient-centered research and care. The study focuses on identifying key life events and their emotional impact on PCC patients, as well as factors influencing these events and their connection to mental well-being.

Who can participate?
We will invite:
1. Participants from the Zurich SARS-CoV-2 Cohort and Zurich SARS-CoV-2 Vaccine Cohort who reported ongoing symptoms or were diagnosed with PCC.
2. Individuals currently enrolled in the Pycnogenol in Post COVID-19 Condition (PYCNOVID) randomized controlled trial.
3. Individuals considered to have PCC enrolled in a study at the University Hospital Zurich.
4. Individuals with PCC recruited through the ALTEA Long Covid Network and Long COVID Schweiz.

Participants must be adults aged 18 years or older, have good knowledge of German, be able to follow the study procedure, and provide informed consent.

What does the study involve?
Participants will take part in a one-time electronic semi-structured survey. This survey will ask about their experiences living with persistent symptoms, any significant life changes or events since they started experiencing symptoms, and their coping and support strategies.

What are the possible benefits and risks of participating?
The study poses minimal risk to participants. The main risk is the potential for unauthorized

access to data, but strict measures are in place to ensure confidentiality and data protection. Participants will not directly benefit from the study, but their contributions will help improve understanding of PCC and guide healthcare professionals, policymakers, and support communities in addressing the needs of those affected. Ultimately, this research could benefit all people living with PCC.

Where is the study run from?
The study is conducted by the Digital & Mobile Health Group at the Institute of Implementation Science in Health Care and the Epidemiology, Biostatistics and Prevention Institute, both at the University of Zurich.

When is the study starting and how long is it expected to run for?
The recruitment period will begin on 25 October 2024 and is expected to end on 28 February 2025. Data collection should be completed by 1 April 2025, with data analyses and final reports expected by 31 January 2026. If the expected sample size is not reached, the study period may be extended with approval from the ethics committee.

Who is funding the study?
The study is funded by the Digital & Mobile Health Group at the Institute of Implementation Science in Health Care and the Epidemiology, Biostatistics and Prevention Institute, both at the University of Zurich.

Who is the main contact?
Dr. Tala Ballouz (tala.ballouz@uzh.ch)

Contact information

Type(s)
Public, Scientific, Principal investigator

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Additional identifiers

Clinical Trials Information System (CTIS)
Nil known

ClinicalTrials.gov (NCT)
Nil known

Protocol serial number
2024-01025

Study information

Scientific Title
Understanding the experiences of living with Long Covid – the “Living with post COVID-19 symptoms” survey

Study objectives
The overall aim of this study is to capture the experience of patients living with post COVID-19 Condition (PCC). The primary objective is to identify categories of life events that patients living with PCC perceive as central. Secondary objectives include evaluating the association of these life events with personal-level characteristics, analyzing how these life events resonated emotionally, identifying personal and professional life changes, and exploring coping and support strategies utilized by participants.

Ethics approval required
Ethics approval required

Ethics approval(s)
approved 20/08/2024, Cantonal Ethics Committee Zurich (Stampfenbachstrasse 121, Zurich, 8090, Switzerland; +41 432597970; admin.kek@kek.zh.ch), ref: 2024-01025

Study design
Observational cross-sectional study

Primary study design
Observational

Study type(s)
Other, Quality of life

Health condition(s) or problem(s) studied
Persons living with post COVID-19 symptoms

Interventions
People with protracted symptoms potentially related to PCC and people who have been diagnosed by a healthcare professional with PCC are invited to tell their story about living with persistent symptoms through a one-time electronic semi-structured survey that includes questions on any perceived life changes and major events or experiences since they started experiencing persistent symptoms, as well as coping and support strategies.

Intervention Type
Not Specified

Primary outcome(s)

Categories of key events (e.g., an event marking a loss of one's usual ability to perform, relationship problems resulting from change in health) that participants have experienced and their emotional valence measured using a one-time electronic semi-structured survey

Key secondary outcome(s))
Measured using a one-time electronic semi-structured survey:
1. Factors (e.g., age, gender, PCC severity or symptom clusters) associated with experiencing key life event categories
2. Mental wellbeing and depressive symptoms associated with the different life events categories
3. Frequency of high-impact life event types (e.g., personal life, work-related etc.)
4. Coping strategies and experienced support

Completion date
01/04/2025

Eligibility

Key inclusion criteria
1. People with symptoms related to PCC or diagnoses with PCC.
2. Adults aged 18 years or older.
3. Good knowledge of German (reading, speaking, and writing).
4. Ability to follow the study procedure.
5. Provided informed consent.

Participant type(s)
Population

Healthy volunteers allowed
No

Age group
Adult

Lower age limit
18 years

Sex
All

Total final enrolment
247

Key exclusion criteria
There are no exclusion criteria.

Date of first enrolment
25/10/2024

Date of final enrolment

28/02/2025

Locations

Countries of recruitment
Switzerland

Study participating centre
University of Zurich, Epidemiology, Biostatistics & Prevention Institute
Hirschengraben 84
Zurich
Switzerland
8001

Sponsor information

Organisation
University of Zurich, Epidemiology, Biostatistics and Prevention Institute

Funder(s)

Funder type
University/education

Funder Name
Universität Zürich

Alternative Name(s)
University of Zurich, Switzerland, University of Zurich, UZH

Funding Body Type
Government organisation

Funding Body Subtype
Universities (academic only)

Location
Switzerland

Results and Publications

Individual participant data (IPD) sharing plan

The data sharing plan will be made available later.

IPD sharing plan summary

Data sharing statement to be made available at a later date