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Study title: An international survey exploring the experiences of healthcare professionals living with Long COVID (with post-exertional malaise/post-exertional symptom exacerbation) and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

INFORMATION LEAFLET

You are invited to take part in a research study. Before you decide whether or not to take part, we would like to explain why the study is being done and what it will involve. Please read the following information and ask us if anything is not clear, or if you would like more information, using one of the contact options listed above.

What is the purpose of this study?

The aim of this study is to explore the experiences of healthcare professionals who develop Long COVID and/or Myalgic Encephalomyelitis /Chronic Fatigue Syndrome (ME/CFS). It is known that many healthcare professionals have or had ME/CFS and/or Long COVID but there is a lack of formal studies in this area.

Why have I been invited?

You have been invited because you have ME/CFS and/or Long COVID (with Post-exertional Malaise (PEM)) and were/are a healthcare professional before developing ME/CFS or Long COVID. We believe, therefore, that you may be eligible to participate in the study. We use the International Consensus criteria for ME/CFS to check if you meet the criteria for ME/CFS and to see if you are therefore eligible to take part in the study if you have ME/CFS. Therefore, please only fill in the survey if you have ME/CFS symptoms listed below:

1. Post-Exertional Neuroimmune Exhaustion (PENE pen′-e) Compulsory (A)

This cardinal feature is a pathological inability to produce sufficient energy on demand with prominent symptoms primarily in the neuroimmune regions. Characteristics are:

1. Marked, rapid physical and/or cognitive fatigability in response to exertion
2. Post-exertional symptom exacerbation
3. Post-exertional exhaustion may occur immediately after activity or be delayed by hours or days.
4. Recovery period is prolonged, usually taking 24 hours or longer. A relapse can last days, weeks or longer.
5. Low threshold of physical and mental fatigability (lack of stamina) results in a substantial reduction in pre-illness activity level.

2. 3 Neurological Impairments: at least 1 symptom from 3 of the 4 symptom categories (B)

1. Neurocognitive Impairments
2. Pain
3. Sleep Disturbance
4. Neurosensory, Perceptual and Motor Disturbances

3. 3 Immune/gastro-intestinal/genitourinary Impairments: at least 1 symptom from 3 of the following 5 symptom categories (C)

1. Flu-like symptoms
2. Susceptibility to viral infections with prolonged recovery periods
3. Gastro-intestinal tract: e.g. nausea, abdominal pain, bloating, irritable bowel syndrome (IBS)

4. Genitourinary: e.g. urinary urgency or frequency, nocturia

5. Sensitivities to food, medications, odours or chemicals

4. 1 Energy metabolism/ion Transport Impairments: 1 symptom (D)

1. Cardiovascular: e.g. inability to tolerate an upright position - orthostatic intolerance (OI)

2. Respiratory: e.g. air hunger, laboured breathing, fatigue of chest wall muscles

3. Loss of thermostatic stability:

4. Intolerance of extremes of temperature

What will happen if I decide to take part?

If you decide to take part, you will be asked to read this Participant Information Sheet and then if you fit the criteria and are happy to complete the survey to click on the link at the end of this participant Information sheet. There are 35 questions to answer, and most are multiple choice quick answers to reduce the energy required to fill out the survey.

The survey is international, and many countries use different terminology for ME/CFS including: Systemic Disease Intolerance Disease (SEID), Chronic Fatigue Immune Dysfunction Syndrome (CFIDS), Post Viral Fatigue Syndrome (PVFS). To this end, we will use the generic term “ME/CFS” so that we can survey everyone who suffers from Post Exertional Malaise (PEM). The UK NICE Guideline defines PEM as “the worsening of symptoms that can follow minimal cognitive, physical, emotional or social activity, or activity that could previously be tolerated. Symptoms can typically worsen 12 to 48 hours after activity and last for days or even weeks, sometimes leading to a relapse.” NICE guideline [NG206] Published: 29 October 2021

At the beginning of the survey you will be asked to consent to this data being collected, collated and published. There will no identifiable personal data collected, and all data will be securely stored in a password-protected University of Liverpool database. The data will be stored for the recommended ten years.

Do I have to take part?

No participation is voluntary, you may refuse to participate. You do not need to tell us why you do not want to take part. If you choose not to participate, your decision will in no way affect your future healthcare.

What are the possible disadvantages and risks of taking part?

There are no disadvantages to taking part, however, it is anticipated that the survey may take up to 15 minutes and there may be a risk of exacerbating your post-exertional malaise. You can stop and restart the survey to allow you to break up this time. Also the topic of survey may be sensitive to you as we will be discussing the impact of ME/CFS or Long COVID on your abilities as a healthcare professional. If you are affected by this we advise you to contact your GP in the first instance, however, there are other organisations that can offer support:

Organisations	
NHS Direct	NHS talking therapies https://www.nhs.uk/service-search/mental-health/find-an-NHS-talking-therapies-service/
The ME Association	www.MEAssociation.org.uk ME Connect: 0800 538 5200
Physiosforme	www.physioforme.com
Long COVID Physio	www.longcovidphysio.com

- 24 hours access https://www.samaritans.org/how-we-can-help/contact-samaritan/
- Free counselling on the NHS https://www.nhs.uk/service-search/find-a-psychological-therapies-service/

Are there any benefits of taking part in this study?

There are no direct benefits to taking part. However, the aim of the study is to explore the experiences of healthcare professionals who develop Long COVID and/or ME/CFS, this information may help the management of these conditions in the future.

Are there any costs involved?

There are no costs involved, and no payment is provided for participation.

Withdrawal options and your rights

Your participation in this study is entirely voluntary and refusal will not affect any health care. You are free to withdraw without giving a reason, without your medical care and legal rights being affected. If you want to withdraw your data from the study, you need to inform the PI by the end of December 2026 at this point all data will be entered into data analysis.

Data protection & confidentiality

The study complies with Government & the University of Liverpool's data protection policy as well as the University's research ethics requirements. The information from the study will be kept in a password-protected university computer database that only the research team will have access to. The data from this study will be retained for ten years. Information will be kept on the University of Liverpool secure databases and will not be stored on the cloud. After 10 years all the online data will be destroyed with the support of IT services

What if things go wrong? Who to complain to.

If you have a concern about any aspect of this study, you should ask to speak with the researchers, who will do their best to answer your questions, or contact the Principal Investigator, Dr Nicola Clague-Baker (Nicola.Baker@liverpool.ac.uk), Tel. 07912950671. If you are not satisfied with the response you receive from the investigator, then there is a formal university complaints procedure.

This involves contacting the Research Ethics and Integrity Office at ethics@liv.ac.uk. When contacting the Research Ethics and Integrity Office, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

The University strives to maintain the highest standards of rigour in the processing of your data. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to lodge a complaint with the Information Commissioner's Office by calling 0303 123 1113.

What will happen with the results of the study?

The results will be analysed and discussed by the researcher and research assistants. The anonymised quotes may be presented in research reports, scientific conferences and/or journals and be made available to people with ME/CFS and Long Covid via the Physios for ME and Long Covid Physio websites. The results may act as baseline information that guides future research by other investigators and the anonymised results of this study will be shared and used by other authorised researchers to support other similar research in the future.

The University processes personal data as part of its research and teaching activities in accordance with the lawful basis of ‘public task’, and in accordance with the University’s purpose of advancing education, learning and research for the public benefit.

Under UK data protection legislation, the University acts as the Data Controller for personal data collected as part of the University’s research. The Principal Investigator acts as the Data Processor for this study, and any queries relating to the handling of your personal data can be sent to Nicola Clague-Baker – nicola.baker@liverpool.ac.uk.

Further information on how your data will be used can be found in the table below.

How will my data be collected?	Online survey
How will my data be stored?	The data will be stored on a secure University database.
How long will my data be stored for?	The data will be stored for the recommended ten years but the recordings will be deleted once the transcription has occurred.
What measures are in place to protect the security and confidentiality of my data?	All data is kept on secure password protected University databases and all transcripts will be anonymous. Information will be kept on the University of Liverpool secure databases and will not be stored on the cloud.
Will my data be anonymised?	Yes
How will my data be used?	The results will be analysed and discussed by the researcher and research assistants. The anonymised quotes may be presented in research reports, scientific conferences and/or journals and be made available to people with ME/CFS and Long Covid
Who will have access to my data?	The PI and research assistants and authorised researchers to support other similar research in the future will have access to the anonymised data
Will my data be archived for use in other research projects in the future?	Yes for 10 years
How will my data be destroyed?	After 10 years all the online data will be destroyed with the support of IT services

Who has reviewed this study?

All research involving human subjects must receive approval from the University of Liverpool Ethics Committee before it can go ahead. Approval does not guarantee that you will not come to any harm if you take part. However, approval means that the committee is satisfied that your rights will be respected, that the study carries no more than minimal risk, and that you have been given sufficient information on which to make an informed decision.

Who is organising and funding the research?

This study is being conducted by a team of experts at the University of Liverpool, Physios for ME and patient and public involvement.

Further information/Key contact details

Principal Investigator: Dr Nicola Clague-Baker at Nicola.Baker@liverpool.ac.uk

If you are happy with the above and have no questions, please complete the survey.

Thank you.

Please follow this link to complete the survey:

https://app.onlinesurveys.jisc.ac.uk/s/liverpool/survey-exploring-the-experiences-of-healthcare-professionals--1