

**Chief Investigator – Dr Nicola Baker (Clague-Baker)**  
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**Study title:**

**An international survey exploring the experiences of professional, semi-professional and high level athletes/sportspeople/dancers with Long COVID 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 professional, semi-professional athletes/sportspeople/dancers with Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). It is known that many athletes/sportspeople/dancers have 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 athletes/sportspeople/dancers before developing ME/CFS or Long COVID. We

believe, therefore, that you may be eligible to participate in the study. Please refer to 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 - <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3427890/>

### **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 29 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, there are 29 questions to answer so this will take up to 20 minutes to complete. There may be a risk of exacerbating your post-exertional malaise.

### **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 athletes/sportspeople/dancers who develop Long COVID and/or ME/CFS which could help to inform management strategies going forwards.

### **Are there any costs involved?**

No

### **Withdrawal options and your rights**

Your participation in this study is entirely voluntary and refusal will not affect any health care.

Unfortunately, it will not be possible to withdraw your data once you have completed the survey as the responses are all anonymous.

### **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. Information to identify you are: your gender and age. All information provided will be kept strictly confidential. The information from the study will be kept in a password-protected university database that only the research team will have access to. The information from this study will be retained for ten years.

### **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. 0151 795 8073. If you are not satisfied with the response you receive from the investigator, then there is a formal university complaints procedure.

### **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 using the JISC system
How will my data be stored?	The anonymous data will be stored on the JISC survey platform online

	and then transferred to the secure University databases.
How long will my data be stored for?	The data will be stored for the recommended ten years.
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 data 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 representatives.

### **Further information/Key contact details**

Principal Investigator: Dr Nicola Clague-Baker at [Nicola.Baker@liverpool.ac.uk](mailto:Nicola.Baker@liverpool.ac.uk)

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

Thank you.

Please follow the link to complete the survey:

<https://app.onlinesurveys.jisc.ac.uk/s/liverpool/survey-exploring-the-experiences-of-professional-semi-profess-1>