Chief Investigator (CI) – Dr Nicola Baker (Clague-Baker)
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1. Study title: The experiences of physiotherapy in the UK for people with Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS) – survey

2. Version number 2. 14/8/2026

3. 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.

4. What is the purpose of this study?

The aim of this study is to explore the experiences of physiotherapy for people with Myalgic Encephalomyelitis /Chronic Fatigue Syndrome (ME/CFS).

5. Why have I been chosen to take part?

You have been invited because you have ME/CFS and have been treated by a physiotherapist. We believe, therefore, that you may be able to take part in the study.

Please refer to the International Consensus criteria for ME/CFS to check if your child meets the criteria for ME/CFS and to see if they are therefore eligible to take part in the study if they have ME/CFS - https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3427890/)

6. Do I have to take part?

No you don't have to take part. You do not need to tell us why you do not want to take part.

If they choose not to participate, their decision will in no way affect their future healthcare.

7. 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 study and are happy to complete the survey to click on the link at the end of this participant Information sheet. There are a range of questions to answer, and most are multiple choice quick answers to reduce the energy required to fill out the survey.

The survey is UK based so 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, processed and published and for the results (no one will know what you have said as it doesn't have your name on the form) being made available for re-use in future studies.

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.

8. What are there any risks in taking part?

There are no problems to taking part, but there are a number of questions to answer so this will take up to 20 minutes to complete. There may be a risk of making your symptoms worse by doing

this. We are sure you are aware but please do pace yourself and manage your symptoms before, during and after the survey. You can stop and continue the survey at another time to allow you to pace.

9. 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 physiotherapy for people with ME/CFS, this information may help the management of these conditions in the future.

10. How will my data be used?

The study complies with Government & the University of Liverpool's data protection policy as well as the University's research ethics requirements. 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.

The anonymised results will be made available for re-use in future studies. 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. The anonymised results will be made available for re-use in future studies.
Who will have access to my data?	The Chief Investigator 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

11. Expenses and/or payments

There are no expected expenses and no payments available.

12. What will happen with the results of the study?

The results will be analysed and discussed by the researcher and research assistants. What you say may be presented in reports, conferences and/or journals and be made available to people with ME/CFS using the Physios for ME website but noone will know you have said that.

13. What will happen if I want to stop taking part?

Withdrawal options and your rights

Their participation in this study is entirely voluntary and refusal will not affect any health care. Unfortunately, it will not be possible to withdraw thier data once they have completed the survey as the responses are all anonymous.

14. What if I am unhappy or if there is a problem?

If you are worried about any part 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, Tel: 0151 794 8290. 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.

15. Who has reviewed this research?

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.

16. Who is organising and funding the research?

This study is being sorted by a team of experts at the University of Liverpool, PhysioforME and patient and public involvement.

17. Further information/Key contact details

Principal Investigator (the person responsible for the smooth running of the study): 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 the link to complete the survey:

https://app.onlinesurveys.jisc.ac.uk/s/liverpool/survey-exploring-the-experiences-of-physiotherapy-for-people--1