

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

**An international survey of experiences and attitudes towards Pacing using a heart rate monitor for people with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome**

**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 and attitudes towards pacing with a heart rate monitor in people with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). People with ME/CFS often use heart rate monitors to pace their activities but there has been very little research exploring the use and peoples experiences of this approach.

**Why have I been invited?**

You have been invited because you have ME/CFS and use Heart rate monitor pacing (HRMP) and we believe, therefore, that you may be eligible to participate in the study.

### **What will happen if I decide to take part?**

If you decide to take part you will be asked to click on this link and answer the questions in this survey:

<https://leicester.onlinesurveys.ac.uk/an-international-survey-of-experiences-and-attitudes-toward-5>

It is assumed that by completing the survey you are consenting 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 Leicester computer. The data will be stored for the recommended five years.

### **Do I have to take part?**

Only if you want to.

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 40 questions to answer so this will take up to 10 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 use of HRMP so your answers might help people with ME in the future.

### **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 be difficult 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 Leicester'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 computer that only the research team will have access to. The information from this study will be retained for five 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 ([njc36@le.ac.uk](mailto:njc36@le.ac.uk)), Tel. 0116 252 3305. If you are not satisfied with the response you receive from the investigator, then there is a formal university complaints procedure. In the first instance write to the chair of the Medicine and Biological Sciences research ethics committee, currently Dr. Chris Talbot ([cjt14@le.ac.uk](mailto:cjt14@le.ac.uk)).

### **What will happen with the results of the study?**

The results will be analysed and discussed by the researcher. The results of the study may also be presented in research reports, scientific conferences and/or journals and be made available to pWME via the PhysiosforME website. The results may act as baseline information that guides future research by other investigators.

### **Who has reviewed this study?**

All research involving human subjects must receive approval from the Medicine and Biological Sciences Research 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 Leicester and the facebook group: ME/CFS: Pacing with a HR monitor.

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

Principal Investigator: Dr Nicola Clague-Baker at [njc36@le.ac.uk](mailto:njc36@le.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://leicester.onlinesurveys.ac.uk/an-international-survey-of-experiences-and-attitudes-toward-5>