

An evaluation of thermal resilience techniques used by Multiple Sclerosis patients?
Adult Participant Information Sheet (Online Survey)

Investigators Details:

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We would like to invite you to take part in our study. Before you decide we would like you to understand why the research is being done and what it would involve for you.

What is the purpose of the study?

The purpose of this study is to gather personal insights on heat and cold temperature sensitivity in Multiple Sclerosis, and specifically, on what methods patients use to cope with the symptom worsening induced by exposure to heat and cold. Ultimately, this knowledge will be relevant to develop patient-centred approaches to ameliorate the burden of temperature sensitivity in MS.

Who is doing this research and why?

This study is being conducted by Jasmine O'Garro as part of a final year research project at Loughborough University (Design School), under the supervision of Dr Davide Filingeri and Miss Aikaterini Christogianni. This research will be useful to develop better guidelines and approaches

to help MS patients cope with the transient symptom worsening that is characteristic of heat and cold sensitivity in this clinical group.

Are there any exclusion criteria?

You will not take part if you have never experienced symptoms worsening due to heat and cold as part of your MS.

What will I be asked to do?

Prior to beginning the survey, you will be required to fill in an informed consent form, the survey will take roughly 15 minutes to complete. Once completed, your responses will be saved and will be accessible by only the named investigators .

Once I take part, can I change my mind?

Yes. After you have read this information sheet and asked any questions you may have, we will ask you to complete an Informed Consent Form, however if at any time, before, during or after the sessions you wish to withdraw from the study please just contact the main investigator. You can withdraw at any time, for any reason and you will not be asked to explain your reasons for withdrawing. If during the filling out of the survey, you wish to withdraw, please close the survey and your data completed to that point will not be used in the study. Once the results of the project have been submitted (May 2019) , it may not be possible to withdraw your individual data.

Will I be asked to attend any sessions and where will these be?

The online survey can be completed remotely through any internet-connected electronic device.

How long will it take?

The survey will take roughly 15 minutes to complete.

Are there any disadvantages or risks in participating?

There are no imminent risks associated in taking part in the online survey. If at any point during the questionnaire, you no longer feel comfortable answering the questions, you will be free to terminate your participation by closing the web-browser and your responses will not be used for the purpose of this research.

Data Protection Privacy Notice

Loughborough University will be using information/data from you in order to undertake this study and will act as the data controller for this study. This means that the University is responsible for looking after your information and using it properly. Loughborough University will keep identifiable information about you until this dissertation project is completed in May 2019 .The University's Data Protection Officer can be contacted at: dp@lboro.ac.uk.

What personal information will be collected from me?

Demographic based information

- Age range
- Sex
- Year of MS diagnosis
- MS Treatment regime

Why is this personal information being collected?

This information will help determining whether certain aspects of temperature sensitivity in MS relates to specific age-ranges, sex, treatment regimes or type of MS.

How long will my personal data be retained?

Loughborough University will hold information securely for 6 years.

Will my taking part in this study be kept confidential?

You will not be required to provide any personal identifiable information (e.g. name and address) and so your participation will remain anonymous and confidential.

How will the data collected from me be used?

The results of the study will form the basis for a BSc Ergonomics (Human Factors Design) dissertation, as well as for scientific publications and conference presentations.

What is the legal basis for processing the data?

You may ask the Project Officer for copies of all papers, reports, transcripts, summaries and other published or presented material. All information will be subject to the current conditions of the General Data Protection Regulations. Under GDPR, we will use 'task in the public interest' along with the "research condition" for special categories of personal data ((MS Health Information : Presents of heat/cold sensitivity and the results of this) , as the lawful basis to process your information.

Under the General Data Protection Regulation (GDPR), some of the personal data which will be collected from you is categorised as "sensitive data". The processing of this data is necessary for scientific research in accordance with safeguards. This means that study has gone through an ethical committee to ensure that the appropriate safeguards are put in place with respect to the use of your personal data.

Will my data be shared with others?

Data collected in the online survey will only be shared with investigators involved with the study.

I have some more questions; who should I contact?

If you have any queries or questions throughout then please contact Jasmine O'Garro at J.ogarro-15@student.lboro.ac.uk .

If you have any questions more generally regarding Data Protection at the University, then please do contact the Data Protection Officer on dp@lboro.ac.uk or write to The Data Protection Officer at Academic Registry, Loughborough University, Loughborough, Leics, UK LE11 3TU.

What if I am not happy with how the research was conducted?

If you are not happy with how the research was conducted, please contact the Secretary of the Ethics Approvals (Human Participants) Sub-Committee, Research Office, Hazlerigg Building, Loughborough University, Epinal Way, Loughborough, LE11 3TU. Tel: 01509 222423. Email: researchpolicy@lboro.ac.uk

The University also has policies relating to Research Misconduct and Whistle Blowing which are available online at <http://www.lboro.ac.uk/committees/ethics-approvals-human-participants/additionalinformation/codesofpractice/> .

If you have taken steps to have a concern or complaint about Loughborough University's handling of data resolved but are still not satisfied you have a right to lodge a complaint with the Information Commissioner's Office (ico), who are the relevant regulator for data privacy and protection matters. The ico can be contacted at Wycliffe House, Water Lane, Wilmslow, SK9 5AF and you will find more information at <https://ico.org.uk>.