

## Participant information sheet



### **The impact of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) on occupational performance**

#### **Participant Information Sheet**

##### **About the study**

The purpose of the research study is to investigate how a person's daily living activities, such as self-care, leisure and productivity, are affected by Chronic Fatigue Syndrome/Myalgic Encephalomyelitis. The aim of the study is to identify how people manage their condition on a day to day basis, and which strategies are most effective in enabling people to manage the condition so that they are able to have a good quality of life.

##### **Some questions you may have about the research project:**

##### **Why have you asked me to take part and what will I be required to do?**

As a member of the MEG group, you have been invited to take part in this research to identify how the condition affects your day to day life. In order to meet the parameters of the research, I would like to question people that have been diagnosed with CFS/ME for twelve months or more.

I would like to ask you some questions to identify your experiences, as part of an audio recorded, one-to-one interview. The interview will take approximately one hour, and will take place at Golborne Library on a day that the group meets, at a time that is convenient for you. There will only need to be one interview.

##### **What if I do not wish to take part or change my mind during the study?**

Your participation in the study is entirely voluntary. You are free to withdraw your interest or participation at any time. Please be aware however that the research will be submitted for a university assessment on of 12<sup>th</sup> April 2019. You can withdraw by emailing me on S1515030@uni.cumbria.ac.uk. You do not have to provide a reason for doing so.

**What happens to the research data?**

Following the interview, the recording will be stored securely on a pen drive, with password protection, and kept in a safe. All recordings will be transcribed to analyse themes and trends. You will be offered the opportunity of reviewing the transcript, prior to the final data collection, which will be anonymised to maintain confidentiality. You will have 1 week to notify me of any changes to the transcript.

The results of the study will be presented to the University of Cumbria on 12<sup>th</sup> April 2019. Consent forms and all personal data will be stored until the completion of the programme, estimated to be 31<sup>st</sup> July 2019, after which it will be securely destroyed and all research data will be kept for a further twelve months to enable me to have the opportunity to use the data for publication or conference presentations. This will be securely destroyed by 31<sup>st</sup> July 2020. A copy of the final report will be available for your perusal.

**How will the research be reported?**

The research will be reported in written form, following the University of Cumbria guidance. Participants will be allowed to access the report upon request. All personal details will be omitted from the research, to maintain anonymity and confidentiality, and results will be referred to by respondent number only.

**How can I find out more information?**

If you would like to take part in the research study, please contact me directly via email, S1515030@uni.cumbria.ac.uk.

**Safeguarding**

If during the interview you disclose information that is considered a safeguarding issue, under the University of Cumbria procedures I will have to refer this to my academic supervisor or an academic lecturer at the earliest convenience.

**What if I want to complain about the research**

Initially you should contact me directly via email or my academic supervisor, Dr Ana Borges Da Costa on ana.borgesdacosta@cumbria.ac.uk.

However, if you are not satisfied or wish to make a more formal complaint you should contact Diane Cox, Director of Research Office, University of Cumbria, Bowerham Road, Lancaster, LA1 3JD. diane.cox@cumbria.ac.uk.

Thank you for taking the time to consider your involvement in this study.