

# <u>Do you have ME/chronic fatigue syndrome? Would you be willing to use your lived experience to help us to improve our research plans?</u>

Researchers often work with people who have lived experience of a medical condition to ensure that this research is suitable for the people it is seeking to help.

We would like to ask you what you think of our plans and how we can improve the documents that we have produced for our research participants (the people who will take part in the research) to ensure that these are as easy to understand and helpful as possible.

Working alongside researchers in this way is known as Patient and Public Involvement and Engagement (PPIE).

The closing date for expressing interest is Monday 12th July 2021

#### What is our research about?

Our research is aiming to explore whether the different ways that couples communicate with each other have an impact (positive or negative) on the bodies biological stress responses (and how stressed individuals actually report feeling) and symptoms of CFS/ME.

The title of the study is: How does interpersonal communication in couples influence stress reactivity and symptoms in people with CFS/ME?

We hope that the results of our research will help health professionals to support people with CFS/ME as well as their romantic partners by helping them to understand how best to support their loved ones. Depending on the results of the research this may be through offering behavioural therapies/ support, or stress management techniques.

The study is part of a funded studentship by the Medical Research Council (MRC).

## Who are we looking for?

We are looking for people who have lived experience of CFS/ME.

We welcome people from a wide range of backgrounds. Please feel free to contact us if you are interested in taking part but would like to discuss ways to make this more accessible for you.

You do not need to have any experience of research or any qualifications to take part. We are interested in your views based on your experience of living with CFS/ME.

There are 4 places available for this 'Patient and Public Involvement and Engagement' (PPIE) group



#### What will you be asked to do/ How long will it take?

You will be asked to look over the study participant information sheet (study information from the people who take part in the study) and study questionnaires (measures participants will need to complete) and make notes to feedback to the researcher (this will take approximately 1 hour).

You will then attend a meeting with the researcher and the rest of the PPI group to share your feedback. The meeting will last approximately 45 minutes-1 hour.

#### Where will it take place?

The meeting will take place online on Zoom. If you have not used zoom before please don't worry, many PPIE groups have started to use zoom for the first time this year. We would be happy to talk you through the process of accessing and will give some instructions for beginners at the start of our meeting.

### **Payment information**

You will be compensated £50 for your involvement. You can pick whether you wish to receive this as a BACS payment (this can take up to 2 months to be processed) or an Amazon voucher (this will be given to you on the day of the PPI group).

### The selection process

If you are interested in taking part, please email <a href="mailto:tarnjit.sidhu@manchester.ac.uk">tarnjit.sidhu@manchester.ac.uk</a> with a short paragraph or two explaining why you would like to be involved. We will confirm whether you have been successful by **14th July.** 

#### Contact details

Tarnjit Sidhu is the main researcher for this study. She is based in the Faculty of Biology, Medicine at University of Manchester. If you have any questions or would like to find out more, please contact her on <a href="mainto:tarnjit.sidhu@manchester.ac.uk">tarnjit.sidhu@manchester.ac.uk</a>