#

# **Data Privacy Notice**

**What is this form about?**

A new law has been made that keeps your information safe- things like your name and where you live. If you decide to take part in the study then we will follow the rules in this new law to make sure your information is safe. This form explains how we will collect your information, how we will record it and how we will use it.

**Who will look after your information?**

Researchers from Oxford Brookes University will look after and store your information. It is their job to make sure that your information does not get lost or given to other people that are not involved in the research. Only those in the research study are allowed to see and use your data.

**Why will we collect and use your information?**

The point of the study is to find out more about a health condition called Myalgic Encephalomyelitis (ME) or Chronic Fatigue Syndrome and how those people that have this health condition experience things. We have chosen to collect your data as you also have this condition. We want to ask you questions so we can find out more about how people similar to you experience life, this will help to write new rules for doctors in terms of how to help and treat you.



**What information will we collect?**

* Your personal information- your name, age, gender (if you were born a boy or girl) and postcode.
* Your speech when we ask you questions during the telephone call or chat with one of our researchers.
* We will ask you questions about your health, how you have been feeling and what has happened since you were told you have this health condition.

**Do you have to give us your information?**

No. You do not have to give us any information. You can choose whether to let us have your information not.

**How long will we keep your information?**

We don’t keep your information forever, only for as long as we need it to help us complete the study. We will carefully destroy all your information 10 years after the study finishes. 

**Will your information be shared?**

We won’t share your information with anyone else without your permission unless the law says that we can or should for your own safety or the safety of other people.

**What are your rights?**

You and your parents have the right to:

* Be told how we use your information.
* Ask to see the information we hold.
* Ask us to change information you think is wrong.
* Ask us to remove information when it’s not needed anymore.
* Ask us to only use your information in certain ways.
* Tell us you don’t want your information to be processed.

**Would you like to know more?**

If you are worried about anything to do with how we have run the study, contact the Chair of the University Research Ethics Committee at ethics@brookes.ac.uk. For more information how we collect, use and secure your information contact the Data Protection Officer at: brookesdpo@brookes.ac.uk or the Information Management team on info.sec@brookes.ac.uk