

**Privacy notice for research participants**

This privacy notice provides information on how Oxford Brookes University collects and uses your personal information when you take part in one of our research projects. Please refer to the research participant information sheet for further details about the study and what information will be collected about you and how it will be used.

**Oxford Brookes University** **(OBU)** will usually be the Data Controller of any data that you supply for this research. This means that we are responsible for looking after your information and using it properly. The exception to this is joint research projects where you would be informed on the participant information sheet as to the other partner institution or institutions. This means that they will make the decisions on how your data is used and for what reasons. You can contact the University’s Information Management Team on 01865 485420 or email [info.sec@brookes.ac.uk](mailto:info.sec@brookes.ac.uk).

**Why do we need your data?**

The aim of this qualitative project is to record the experiences and opinions of severely- affected young people (aged 9-18) with Myalgic encephalomyelitis (ME)/Chronic fatigue syndrome (CFS) and their families/carers through focus groups and semi-structured interviews in order to help inform the development of the National Institute for Health and Care Excellence (NICE) guidelines. The data provided will help to inform the guidelines on the following topics: Identification of your condition and the assessment process before diagnosis; The process of the diagnosis of ME/CFS; the management and support they (and their families) have received regarding their ME/CFS; How their ME/CFS is monitored and reviewed; What information, education, and support for people with suspected or diagnosed ME/CFS and their families and carers was available and how helpful it was; what information, education and support for health and social care professionals is needed to help them manage their condition well.

**OBUs legal basis for collecting this data is:**

* You are consenting to providing it to us; and / or,
* Processing is necessary for the performance of a task in the public interest such as research.

**If the university asks you for sensitive data such as; racial or ethnic origin, political opinions, religious or philosophical beliefs, trade-union membership, data concerning health or sexual life, genetic/biometric data or criminal records OBU will use these data because:**

* You have given OBU explicit consent to do so; and / or
* Processing is necessary for scientific or research in the public interest.

**What type of data will Oxford Brookes University use?**

Data being gathered for the study includes demographic information (gender, postcode, age), contact details (telephone and email) and qualitative data from interviews (your child/adolescents’ speech recorded and transcribed into an electronic document and your responses recorded as online survey data).

**Who will OBU share your data with?**

Only the researchers at Oxford Brookes will have access to the data you provide during this research.

**Will OBU transfer my data outside of the UK?**

No

**What rights do I have regarding my data that OBU holds?**

* You have the right to be informed about what data will be collected and how this will be used
* You have the right of access to your data
* You have the right to correct data if it is wrong
* You have the right to ask for your data to be deleted
* You have the right to restrict use of the data we hold about you
* You have the right to data portability
* You have the right to object to the university using your data
* You have rights in relation to using your data in automated decision making and profiling.

**Where did OBU source my data from?**

The data collected will be provided by yourself. Contact information (Name, email and telephone number) will be collected by a member of Oxford Brookes when you provide informed consent. Research data will be collected when completing the interviews or focus groups (via voice recorder).

**Are there any consequences of not providing the requested data?**

There are no consequences of not providing data for this research. It is purely voluntary.

**Will there be any automated decision making using my data?**

There will be no use of automated decision making in scope of UK Data Protection and Privacy legislation.

**How long will OBU keep your data?**

In line with Oxford Brookes policies data generated in the course of research must be kept securely in paper or electronic form for a period of time in accordance with the research funder or University policy.

**Who can I contact if I have concerns?**

In the event of any questions about the research study, please contact the researchers in the first instance (contact details in the study participant information sheet).  If you have any concerns about the way in which the study has been conducted, contact the Chair of the University Research Ethics Committee at [ethics@brookes.ac.uk](mailto:ethics@brookes.ac.uk). For further details about information security contact the Data Protection Officer at: [brookesdpo@brookes.ac.uk](mailto:brookesdpo@brookes.ac.uk) or the Information Management team on [info.sec@brookes.ac.uk](mailto:info.sec@brookes.ac.uk)