

ME/CFS is highly disabling and affects an enormous number of people. We're doing a DNA study to find biological causes of it. And if you're 16 or over, live in the UK and have ME/CFS, you can take three simple steps to help us.

1. AGREE TO TAKE PART IN DECODEME

Read the information about the study, ask any questions and decide if you want to join.

2. TAKE OUR QUESTIONNAIRE

We ask about your symptoms and for other information, such as your age. Your answers will help us create the world's biggest set of data on ME/CFS, helping researchers, doctors and politicians understand the disease better. Your answers will also tell us whether we ask for your DNA sample. As in all medical research, we don't look at everyone with a particular illness – we look at a narrower group, which gives a clearer picture for the science.

3. SPIT AND POST

If you are also asked to provide a DNA sample, we'll mail you a spit kit and you just spit in the tube and mail it back to us. Then we've got your DNA and can do the science!

SEVERELY AFFECTED OR CAN'T TAKE PART ONLINE? WE CAN SEND YOU PAPER DOCUMENTS AND YOU CAN ASK OTHERS TO HELP YOU.

- In this research study we will use information from you. We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study.
- Everyone involved will keep your data safe and secure. We will also follow all privacy rules. At the end of the study we will save some of the data for future research. We will make sure no-one can work out who you are from the reports we write.
- It's important that you understand why we're doing the research and what it will involve, so that you can make a proper decision about whether to take part. So please take the time to read the information in this document carefully before you make your mind up.

- If anything isn't clear, or if you'd like further information, please contact us or take a look at our website at www.DecodeME.org.uk.

**DecodeME aims to help understand ME/CFS
and lead towards treatments**