Take part in our survey and help advance a diagnostic blood test for ME/CFS

Why do we need your feedback?
MEAction UK is working with the research team at the **University of East Anglia (UEA) Medical School** to assist in developing a research application to be submitted to the **Medical Research Council (MRC)**. To help them secure funding we just need approximately five-ten minutes of your time to complete this questionnaire.

The research team has received positive initial feedback on a diagnostic blood test called **EpiSwitch®** they are developing - see more details below. They now want to build on that by asking you to help with the funding application to the **MRC** by completing this questionnaire. To build the funding application we need to prove what a diagnostic test would mean for people living with ME/CFS.

What is the research hoping to achieve?
The **EpiSwitch®** test has been designed to diagnose people with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). The initial study (results published in the *Journal of Translational Medicine*) was led by **UEA** in partnership with **Oxford BioDynamics**. It used cutting edge 3D genomic technology, called **EpiSwitch®**, to look at how DNA is folded inside blood cells. Just like origami, the shape and folds of DNA control which genes are switched on or off.

The **EpiSwitch®** test involves a blood sample taken by a health professional and sent to a special laboratory for processing.

Who should complete this questionnaire?

- If you have ME/CFS we want to hear from you! The questionnaire can also be completed by those who care for someone with ME/CFS on behalf of the person they care for. It will take just approximately five-ten minutes of your time.
- Please return your completed survey by **Friday 27 February 2026**.

How will the results be used?
By completing the questionnaire you are giving your consent for **UEA Medical Team** to use the anonymised responses in reports and the **MRC** application.

What will happen with the data captured?
The data will be analysed by **MEAction UK** and provided to **UEA Medical School** to inform the development of the research application.

Want to know more?

If you require more information prior to completing this questionnaire please contact **uk@meaction.org.uk**

Further information about the initial results from the research into the EpiSwitch® test can be found here: https://link.springer.com/article/10.1186/s12967-025-07203-w

1. **Which of the following best describes you?**

   Check all that apply.

   ☐ I have ME/CFS
   ☐ I care for someone with ME/CFS

2. **If you are completing the questionnaire on behalf of someone with ME/CFS, are you the person's ...?**
   Please respond to the remainder of the questionnaire on behalf of the person with ME/CFS.

   Mark only one oval.

   ○ Parent or legal guardian
   ○ Child
   ○ Sibling
   ○ Husband/wife/partner
   ○ Other family member
   ○ Friend
   ○ Carer
   ○ Other

3. **The EpiSwitch® is a diagnostic test which requires a blood sample taken by a health professional and sent to a special lab. Based on the information provided about the EpiSwitch®, which of the following best describes your initial reaction to the proposed research?**

Dropdown

Mark only one oval.

○ Very positive
○ Positive
○ Neither positive nor not positive
○ Not positive
○ Not at all positive
○ Don't know

4. **Thinking of your response to the previous question, please provide feedback on the reasons for your response. This may include what you perceive to be the strengths and/or weaknesses associated with EpiSwitch® and/or the development of a diagnostic test for ME/CFS.**

5.

To what extent do you agree or disagree with each of the following statements. The development of as accurate diagnostic test for ME/CFS would ...

Mark only one oval per row.

	Agree strongly	Agree	Neither agree nor disagree	Disagree	Disagree strongly	Don't know
... help healthcare professionals support people with ME/CFS	○	○	○	○	○	○
... reduce the misdiagnosis of ME/CFS	○	○	○	○	○	○
... reduce the stigma around ME/CFS	○	○	○	○	○	○
... encourage research into ME/CFS by identifying people known to have ME/CFS	○	○	○	○	○	○

6. **How likely would you be to take a validated EpiSwitch® blood test if it was offered on the NHS?** Dropdown

Mark only one oval.

○ Very likely
○ Quite likely
○ Neither likely nor not likely
○ Not likely
○ Not at all likely
○ Don't know

7. **Please provide feedback on your response to the previous question in the space below.**

_____
_____
_____
_____
_____

8. **How likely would you be to take a validated EpiSwitch® blood test if it was not available on the NHS but was available privately in the UK at a cost of approximately £1000?** Dropdown

Mark only one oval.

○ Very likely
○ Quite likely
○ Neither likely nor not likely
○ Not likely
○ Not at all likely
○ Don't know

9. **Please provide feedback on your response to the previous question.**

10. **Which of the following would you select to describe yourself?** Dropdown

Mark only one oval.

- ○ Female
- ○ Male
- ○ Prefer to self-describe
- ○ Prefer not to say

11. **If you selected self-describe in response to the previous question, please tell us how you describe yourself.**

12. **In which age range are you?**

Mark only one oval.

○ Under 16
○ 16-25
○ 26-35
○ 36-45
○ 46-55
○ 56-65
○ 66+
○ Prefer not to say

13. **Where are you usually resident?**

Mark only one oval.

○ England
○ Northern Ireland
○ Scotland
○ Wales
○ Outside the UK
○ Prefer not to say

14. **Have you been given a diagnosis of ME, ME/CFS or CFS/ME by a health professional?**

Mark only one oval.

○ Yes
○ No
○ Unsure/don't know
○ Prefer not to say

15. **How long have you had ME/CFS?**

Mark only one oval.

○ Less than 6 months
○ Between 6 months and 1 year
○ Between 1 and 3 years
○ Between 3 and 5 years
○ Between 5 and 10 years
○ Between 10 and 20 years
○ Over 20 years
○ Unsure/don't know
○ Prefer not to say

16. **How severe is your illness or the illness of the person for whom you are responding to this questionnaire? Please choose the group you fit most often, or that best describes how severe your illness is overall, even if the detail doesn't exactly match your experience.**

Mark only one oval.

○ Mild – People with mild ME/CFS care for themselves and do light domestic tasks (sometimes needing support) but may have difficulties with mobility. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often have reduced hours, take days off or use the weekend to cope with the rest of the week.

○ Moderate – People with moderate ME/CFS have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level of symptoms and ability to do activities. They have usually stopped work or education, and need rest periods, often resting in the afternoon for 1 or 2 hours. Their sleep at night is generally poor quality and disturbed.

○ Severe – People with severe ME/CFS are unable to do any activity for themselves or can carry out minimal daily tasks only (such as face washing or cleaning teeth). They have severe cognitive difficulties and may depend on a wheelchair for mobility. They are often unable to leave the house or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed and are often extremely sensitive to light and sound.

○ Very severe – People with very severe ME/CFS are in bed all day and dependent on care. They need help with personal hygiene and eating and are very sensitive to sensory stimuli. Some people may not be able to swallow and may need to be tube fed.

○ Unsure/don't know

○ Prefer not to say

17. **Would you like to take part in further research to inform the development of the EpiSwitch®?**

Mark only one oval.

○ Yes, please provide your contact details below and then click submit

○ No, if you select this option please now click submit

○ Unsure/don't know, if you select this option please now click submit

18. **If you would like to take part in further research about the EpiSwitch®, please add your name and email here. Your details will not be shared with anyone else and your responses will not be linked to your personal data.**

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