



Invitation to Keeping ME Warm research

Action for ME and [National Energy Action](#) are working together to better understand experiences of using energy at home, and the needs of people living with ME/CFS or Long Covid. This might be you, or someone else that lives with you. If this does not apply to you then you can disregard this invitation.

By energy, we mean fuels such as gas, electricity and any others (eg. oil) used to heat, cool or power lights and appliances. We refer to this as home energy. We will ask about comfort at home, home energy use and management, affordability and how it may affect your health and wellbeing, including symptoms of ME/CFS or Long Covid.

You are invited because you have previously received advice or support from us. The project is funded by the Energy Industry Voluntary Redress Scheme.

Summary of key points

- This cover letter invites people affected by ME/CFS or Long Covid to take part in the Keeping ME Warm questionnaire.
- The questionnaire aims to gather views and experiences about using electricity, gas or other fuels at home, comfort, affordability, and the impact on health and wellbeing.
- Participation is voluntary.
- Responses will help shape future support for people affected by ME/CFS or Long Covid.
- The letter asks recipients to read the Research Information Sheet before deciding to take part.
- It provides contact details for questions, alternative formats, and additional support.

What we are asking you to do

Your views and experiences are important to us. We are inviting you share these with us by taking part in our questionnaire. Your answers will help inform the design and delivery of advice and support for people affected by ME/CFS or Long Covid.

- Please take your time. You do not need to complete the questionnaire immediately. You can pause and come back to the questionnaire if you need to.
- As a thank you, you can choose to enter a prize draw to win one of three shopping vouchers: £100 voucher, £50 voucher, or £25 voucher.

- Prize vouchers can be a supermarket of your choice or a Love2Shop voucher that can be spent in multiple retailers. You can also select whether you would like a physical or online voucher.

Before you decide

Please read the [Research Information Sheet](#) before deciding whether to take part.

This explains what the research is about, what data we will collect, how we will use it, and how we will look after it. This includes information about your personal data.

Your privacy is important to us

You have been sent this invitation by Action for ME. Your personal data has not been shared outside the charity. Any information we have stored about you has been recorded with your consent and in line with Action for ME's [privacy policy](#).

Completing the questionnaire

You can [complete the questionnaire here](#).

You do not have to take part if you do not want to. If you decide not to take part, this will not affect any support you have received, or may receive, from Action for ME or National Energy Action.

The deadline for completing the questionnaire is **Thursday 31 December 2026**.

Other ways of taking part

To make taking part as easy as possible we have other ways that you can get involved in the research. As well as the questionnaire, these are:

- interviews
- diaries.

You can read more about these activities in the [Research Information Sheet](#). You can take part in these activities as well as completing the questionnaire, or instead of completing the questionnaire.

There are options at the start of the questionnaire that will enable you to choose how you'd like to take part.

Reasonable adjustments can be made for you to take part in these activities.

If you need further support

If you have any questions about this research, or would prefer a different format, contact our Projects and Participation Senior Practitioner Avril McLean [by email](#). You can ask for a paper copy, a large print version, or to complete the questionnaire by telephone.

If you need support regarding ME/CFS or Long Covid, please contact Action for ME's [Information and Support Service](#) by [email](#) or call on 0117 927 9551 (choose option one) between 10.30am and 3pm, Monday to Thursday (excluding bank holidays), to request a call-back.

If you need support with affording gas, electricity, or other fuels, please contact [National Energy Action](#).

Thank you for your time and consideration.