



Keeping ME Warm project

Research Information and Data Protection

It is important to understand what taking part in our research will involve and what data we will collect, process and share about you. Your privacy is important to us. In this Research Information Sheet, you will find sections on:

1. Summary of key points
2. What is this research about?
3. Who is involved?
4. Why am I being asked to take part?
5. What does taking part involve?
6. What data will you collect?
7. Will you look after my information and data?
8. What will happen to the result of the evaluation?
9. Terms and conditions of accepting acknowledgements of participation.

Please take some time to read the text below, at your own pace, before carrying on or deciding on your participation. Thank you.

Summary of key points

- The Keeping ME Warm research explores how living with ME/CFS or Long Covid affects the use of gas, electricity and any other fuels used to heat, cool or power your home and appliances. The project is led by National Energy Action with Action for ME, funded by the Energy Industry Voluntary Redress Scheme, and runs from July 2026 to June 2028.
- Taking part is voluntary, and you can withdraw at any time without affecting any support from National Energy Action or Action for ME.
- Activities include a questionnaire, interviews or diary entries; not everyone who expresses interest will be invited to every activity.
- The project collects personal data, special category data and research responses, including information about health, finances and home energy use.
- Personal data will be stored securely by National Energy Action (not Action for ME), shared only within the Project Team (incl. Action for ME) where needed, and processed on the basis of consent.

- Research findings will be reported anonymously; personal data will not be included in published reports without explicit consent.
- Personal data collected for research will normally be deleted within 12 months of the project ending, while anonymised data may be retained indefinitely.
- Participants may receive acknowledgements such as prize draw entries or vouchers, subject to the terms and conditions at the end of the document.

1. What is this research about?

- The Research Project is called **Keeping ME Warm** and aims to understand experiences of people living with ME/CFS and Long Covid, and how these experiences might shape gas and/or electricity use at home. By gas and/or electricity use at home we mean gas, electricity or other fuels you may use to heat and power your home for warmth, cooling or appliances.
- We're interested in understanding how you manage home energy use, and what support you might need to stay to comfortable and manage energy costs.
- Your insights will help us and our partners learn from your experience and understand a range of views on support needs.
- Your feedback is very valuable and will be used to inform the delivery of services for people affected by ME/CFS or Long Covid in future.
- The project will run from July 2026 to June 2028.

2. Who is involved?

- National Energy Action (NEA) is an independent charity (registration number 290511) that campaigns for warm homes. NEA's aim is to ensure that everyone can afford to live in a warm and safe home.
- We are working with Action for ME, a charity in the UK that provides support, including healthcare, to people affected by ME.
- Together NEA and Action for ME are referred to as the '**Project Team**'.
- The project is funded by the Energy Industry Voluntary Redress Scheme.

3. Why am I being asked to take part?

- You are being asked because you have previously received advice or support from Action for ME or NEA, or you receive newsletters or information about their activities or events.
- Taking part in this research is completely voluntary. You do not have to take part, but your contribution is valuable.
- Deciding not to take part will not affect the assistance that you have received or might be due to receive from NEA or Action for ME. You can withdraw from this research at any time without giving a reason by contacting researchteam@nea.org.uk

4. What does taking part involve?

- There are a range of opportunities to take part in our research, including:
 - **A short questionnaire:** The deadline for completing the questionnaire is Thursday 31 December 2026.
 - **Interviews:** This would involve a short conversation (via phone) with you to offer you the chance to give more detailed feedback on how you use gas/electricity/other fuels at home and how your health impacts home-energy use. We will aim to conduct these between November 2026 and February 2027.
 - **Diaries:** These consist of a booklet containing 6 entries to complete one per week if you have the time or energy to do so. You can do this any time between November 2026 and February 2027. There is the option to submit more entries if you feel able to. Diary entries provide you with the chance to offer insights into how you use gas/electricity/other fuels at home, how your health affects the use of these fuels, and some of the barriers you might face.
- Each activity is different and taking part is voluntary. You can take part in these activities as well as completing the questionnaire, or instead of completing the questionnaire. Not all individuals that express their interest will be invited to take part in every activity.
- 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.
- For some research activities, participants will have their participation acknowledged by receipt of gift voucher(s) as a thank you. The type of acknowledgement will depend on the activity and will be detailed in your invitation to each activity. This will be a prize draw to win up to £100 in shopping vouchers entered via the questionnaire, up to £25 gift voucher for an interview, or up to £50 for completing a diary. Terms and Conditions can be found at the end of this document.

5. What data will you collect?

- NEA will collect, store, and process data on your experience of living with ME/CFS or Long Covid, and how this might shape how you use energy at home. This may include questionnaire responses, written diary entries, or interview responses. This depends on the type of activity to which you have been invited.
- NEA will also collect, store and process your personal data, such as your name, address, and contact details.
- Special category personal data: This includes data such as information about your health or financial circumstances. Because this data is more sensitive, we must take great care of it and have your consent to collect, store and process it for

research purposes. If you wish to join the project, we ask for your consent to do this in the enclosed questionnaire.

6. Will you look after my information and data?

- Yes. All your personal data (data that can identify you) that is collected, stored and processed by NEA during this research will be treated carefully and stored securely.
- Personal data and responses will be processed by NEA and may be shared with project partner Action for ME. This may be for research purposes or to follow up with you on your responses or where you have asked for support. NEA will not share your personal data collected in this research with any other organisations.
- NEA is registered with the Data Commissioner. Personal data will be treated in accordance with the Data Protection Act and General Data Protection Regulations 2018.
- The Legal Basis on which we will collect and process data you provide to us by participating in research is (your) Consent.
- The Project Team will delete your personal data collected for the purposes of this research within 12 months of project end. NEA/Action for ME may retain your personal data if you are already registered to receive advice, services or communications from us.

7. What will you do with my information and data?

- We will use your data to undertake analysis and write reports about the experiences of people living with ME/CFS or Long Covid, and the impact this might have on how they use energy at home. No names or personal data will be included in these reports.
- Your individual responses will be put together with responses from others and made anonymous for the purposes of reporting. These reports may be shared, published and made available publicly. No names or personal data will be included in these reports.
- Data retention:
 - We will not store your personal data for longer than is necessary.
 - If you are selected, or opt to take part in research activities, at the end of the project personal data will be anonymised for statistical and research purposes and may be retained indefinitely.
 - Personal data (including audio and electronic files) will be safely and securely destroyed within 12 months of project end, except where we are legally/contractually obliged to retain it and/or transmit it to a regulatory or government body, or retention of your personal data is reasonably necessary for us to carry out our charitable objectives. For further information please contact info@nea.org.uk

- If you are not selected to take part in research activities, or opt out from doing so, we may retain your name and research participant number to demonstrate compliance with contractual obligations. After which, it will be deleted.
- Retained data: Anonymised data (that which cannot be used to identify you) may be retained indefinitely for research purposes and/or used in published research and reports.

8. What will happen to the results of the evaluation?

- The results of the research will be used to provide anonymised analysis and write reports that will/may be published and/or shared with others. These reports will present the experiences and views of those that took part in the research anonymously and will make recommendations about the types of advice, support or services that should be provided to people in similar situations. We may also use anonymous individual quotes or case studies to provide accounts of the experiences of those who use NEA's services.
- Published reports and/or documents will not personally identify anyone that took part in the research without their explicit consent.

Thank you for your time.

Terms & Conditions of accepting acknowledgements of participation.
PRIZE DRAWS

1. The prize draw is open to anyone who opts into the prize draw and enters their personal contact information in the questionnaire. On entering the prize draw, you are deemed to have accepted and agreed to be bound by these terms and conditions.
2. The prize draw is free to enter and is being held and managed by National Energy Action. Unless stated otherwise on your questionnaire, prizes are drawn on the first Monday of December and first Monday of June. You will be entered into the next available draw following receipt of your questionnaire. Winners are selected at random by a random number generator on a computer. You must provide your contact details to be entered in the draw and must be aged over 18.
3. Where winners cannot be contacted after reasonable attempts prizes will be reallocated. Only one entry allowed per household. Entrants must be UK residents. The prize draw is not open to employees of National Energy Action or Action for ME.
4. In entering the prize draw, you confirm that you are eligible to do so and eligible to claim the prize. National Energy Action may require you to provide proof that you are eligible to enter the prize draw and claim the prize.
5. Names and postal or email addresses provided during the course of the free draw may be passed onto third party suppliers only insofar as they are required for delivery of the prize to winners.
6. We will retain your personal data for the purposes of administering the prize draw for no longer than 30 days, after which it will be securely deleted from our systems unless you are a Research Project participant in which case data will be retained as stated in your Research Information Sheet.
7. We accept no responsibility for entries not successfully completed due to a technical fault or malfunction, computer hardware or software failure, satellite, network or server failure of any kind, and we reserve the right to substitute the prize with another prize of similar or greater value if circumstances beyond our control makes it necessary. Prizes are non-exchangeable, non-transferable and no cash alternative is offered.
8. Our decision regarding any aspect of the free draw is final. No correspondence will be entered into about it. National Energy Action must either publish or make available information that indicates that a valid award took place. To comply with this obligation, National Energy Action will send the surname and county of the prize draw winner to

anyone who emails ResearchTeam@nea.org.uk within one month after the closing date of the prize draw. If you object to any or all of your surname and county being published or made available, please contact us at ResearchTeam@nea.org.uk. In such circumstances, National Energy Action must still provide the information and winning entry to the Advertising Standards Authority on request.

9. Entrants are responsible for understanding how prize values may impact on any tax liabilities or benefits. We accept no responsibility in this regard. Insofar as it is permitted by law, we will not be responsible for, or liable to compensate winners for, or accept any liability for any loss, damage, personal injury, or death occurring as a result of taking up the prize except where it is caused by our negligence.

10. We reserve the right to refuse entry or refuse to award the prize to anyone in breach of these rules.

OTHER ACKNOWLEDGEMENTS (e.g., interview or diary participant thank you vouchers)

1. Names and postal or email addresses of research participants may be shared with suppliers only insofar as they are required for delivery of the thank you voucher to participants.

2. We reserve the right to substitute the acknowledgement with another of similar or greater value if circumstances beyond our control makes it necessary.

3. All acknowledgements are non-exchangeable, non-transferable and no cash alternative is offered.

4. Recipients are responsible for understanding how acknowledgements may impact on any tax liabilities or benefits. We accept no responsibility in this regard. Insofar as it is permitted by law, we will not be responsible for, or liable to compensate recipients for, or accept any liability for any loss, damage, personal injury, or death occurring as a result of accepting the acknowledgement except where it is caused by our negligence.