Information Leaflet for Development of HSE National Clinical Guideline for Myalgic Encephalomyelitis (ME)

Why We Are Developing This Guideline

The HSE is developing a National Clinical Guideline to support the recognition, diagnosis, treatment and management of ME in Ireland.

This guideline aims to support:

- Healthcare professionals to recognise, diagnose, treat and manage ME
- People living with ME through diagnosis and in accessing appropriate treatment, care and support

This guideline aims to promote:

- Consistent and transparent care
- Evidence-informed practice based on the best available research and lived experience
- Shared decision-making between healthcare professionals and people living with ME

The overall aim is to improve health and social care outcomes and experiences for patients and service users.

The perspectives of people living with ME will help ensure that the guideline reflects real-world experiences and supports meaningful improvements in care.

Why Your Voice Matters

Lived experience is central to this work. We recognise that people living with ME bring knowledge that cannot be found in scientific evidence alone. Your contributions will help ensure that the National Clinical Guideline is informed by both research evidence and an understanding of what it is like to live with ME.

Your insights can help to:

- Ensure recommendations are informed by the lived experience of ME
- Consider how recommendations may be understood and experienced in practice

We only ask you to share your own experiences. You are not expected to represent all people with ME.

What to Expect

As a member of a Lived Experience Group, you can expect to:

- Attend an introductory information meeting, expected to last approximately 45 minutes. The introductory information meeting will provide an opportunity to meet the people leading the Lived Experience Group and others living with ME, to learn how the group will work, and to ask any questions

- Attend a Lived Experience Group Meeting, expected to last 90 minutes, including a break

- Receive meeting materials and discussion questions in advance to allow time for review and preparation

- Share your experiences during discussions, if you feel comfortable doing so

Participation is voluntary. You are encouraged to contribute in a way that feels manageable and appropriate for you.

We understand that health and energy levels may fluctuate. We will be as flexible as we can to support your participation and ensure your voice is heard if you wish to contribute.

Support

We are committed to creating a respectful, inclusive and supportive environment

Support includes:

- A named contact person for any questions or concerns
- Information provided in clear, accessible language
- Consideration will be given to health and accessibility needs
- Guidance and assistance with preparing for an online meeting

Confidentiality

All members are asked to respect the privacy and confidentiality of discussions within the Lived Experience Group.

Draft documents shared during meetings are confidential until publication.

Further Information

If you would like to discuss participation before deciding whether to take part, please contact us at me.clinicalguideline@hse.ie