



Strategic Priorities: April 2022 - March 2023

Who we are

#MEAction Scotland, an affiliate of #MEAction UK, is a grassroots, volunteer-led movement working towards improving the lives of the estimated 21,000 people in Scotland with myalgic encephalomyelitis (ME). ME is a complex, chronic disease that presents with symptoms in multiple body systems and is recognised by the World Health Organization as a neurological disease.

The estimated cost of ME to the UK economy is at least £3.3 billion annually, the equivalent of £17,000 per patient, according to research¹ conducted in 2017.

Our Vision is that politicians, health and social care professionals, and the people of Scotland understand and support people with ME and treat them with respect.

Our Aim is to address the health inequalities that people with ME experience in Scotland.

Our Purpose is:

- To build a stronger ME advocacy community in Scotland
- To raise awareness of the devastating impact of ME
- To campaign for effective support for adults and children and young people with ME.

There are two core publications underpinning our strategic priorities for 2022\23:

- The NICE guideline on the diagnosis and management of ME/CFS² was published in October 2021. Its evidence-based recommendations have been broadly welcomed by #MEAction Scotland. The Scottish Government announced in January 2022 that it had commissioned consultations with key stakeholders to identify how the NICE guideline should be implemented in Scotland (see Lobbying section).
- The Briefing of the ME/CFS healthcare needs assessment (HCNA), published by Public Health Scotland in December 2020³ reviewed the 2010 healthcare needs assessment of adults with ME/CFS. The 2020 report concluded that “that there has been little to no progress on ME-CFS diagnosis and treatment and care pathways in Scotland since 2010” and stated that the recommendations of the 2010 report remained valid.

¹ [2020Health-Counting-the-Cost-Sept-2017.pdf \(meassociation.org.uk\)](#)

² [Myalgic encephalomyelitis \(or encephalopathy\)/chronic fatigue syndrome: diagnosis and management \(nice.org.uk\)](#)

³ [ME-CFS healthcare needs assessment: Briefing at 18 December 2020 \(scotphn.net\)](#)



Partnership working

#MEAction Scotland will continue to work in partnership with individuals and organisations who are aligned with our purpose. #MEAction Scotland is a member of Forward-ME, the Neurological Alliance of Scotland and the Health and Social Care Alliance Scotland.

We have created strong relationships with charities and other organisations that support people with ME in Scotland. We attend regular meetings with a group of stakeholders to discuss key issues and are currently working in partnership on a project led by Action for ME to promote Dr Nina Muirhead's ME/CFS CPD training module in Scotland. In the coming year we will continue to identify areas where we can be stronger together, for example combatting misinformation around ME and raising awareness of the new NICE guideline.

Long COVID

There is a new cohort of chronically ill people who have developed long COVID, an illness that is not yet fully understood. Some long COVID patients have a key symptom which overlaps with ME, called post-exertional malaise (PEM). PEM is the worsening of symptoms following even minor physical or mental exertion. Many long COVID patients are experiencing similar stigma to that faced by the ME community, reporting disbelief and dismissal from some healthcare professionals.

#MEAction Scotland:

- Recognises the problems and distress caused by healthcare professionals who do not believe patients' accounts
- Anticipates that the recognition, funding of and research into long COVID could be beneficial to people with ME
- Will campaign for both conditions to gain from these mutual benefits and ensure that people with ME and people with long COVID who have PEM receive the care and research they deserve
- Will review its strategy towards long COVID as new evidence emerges in relation to ME.

Building a stronger ME advocacy community

As a grassroots movement, it's important that #MEAction Scotland engages with and empowers the ME community and its allies across Scotland. We recognise that many people with ME will never be able to volunteer with us or take part in advocacy in the way they might want, so we aim to provide a range of ways to be part of our work.



Community engagement

In order to share opinions and experiences with each other, we are developing more ways to engage with us. We will be sharing updates about our activity, and Scotland specific issues, regularly on social media to be transparent about our work and give the community the opportunity to comment.

We aim to hold virtual community calls every three months. This will help us connect more directly with people who are unable to volunteer with us but are engaged with the cause. By making space for a live conversation, we hope to facilitate discussions about what is needed for people with ME in Scotland and get feedback about our planned activities. This will help ensure our work is led by the needs of the people it affects.

Online campaigning

For many people with ME, attending events isn't possible, so online campaigning will always be a key element of our advocacy work which will support our lobbying activities. We will continue to look for opportunities to create straightforward, clear actions for the community to take part in - such as sharing social media posts, signing petitions and emailing MSPs - which allow more people to be part of our movement.

Millions Missing - May 2022

This year Millions Missing, #MEAction's annual global call to action, will be held in two parts. In May we will come together virtually to connect with ME advocates around the world. #MEAction Scotland will take part in a global online event that aims to celebrate and empower the ME community and strengthen our advocacy.

Raising awareness of the impact of ME

All our activities contribute to raising awareness of ME and its impact. To achieve our vision, we need to build awareness across a range of different audiences who we will target through press and broadcast media, as well our online activity and direct campaigns.

#MEAction Scotland will prioritise spreading awareness of:

- The changes in the recommendations of the 2021 NICE guideline. A widespread understanding of the dangers of exercise is urgently needed.
- The immediate need for effective, ring-fenced funding for medical care for people with ME.



Key audiences

To raise awareness of the above points, the following key audiences will be targeted:

1. **#MEAction supporters and people with ME who engage with us through social media**

We will engage with this audience through the methods listed in the above section - Building a stronger ME advocacy community.

2. **The medical and other healthcare professionals**

We will raise awareness of the NICE guideline through our engagement with medical schools and partnership work with Action for ME to disseminate Nina Muirhead's CPD module in Scotland. Our priorities for additional training and educational resources are described in the next section..

3. **Scottish Government - specifically Ministers and the Clinical Priorities Unit in the Healthcare Quality and Improvement Directorate**

We will engage with these specific people through meetings with the Clinical Priorities Unit and with relevant Ministers. #MEAction Scotland will seek specific commitments for government actions on the issues identified in the next section. We will provide updates on this progress to the wider community and use our media campaigns to increase pressure on the government where relevant.

4. **Members of Scottish Parliament (MSPs)**

We will continue to work with MSPs of all political parties. People with ME and wider allies can also help us reach this audience by contacting their MSPs directly, and we will ask them to do this when needed.

We will seek to raise awareness through events in and around the Parliament by asking MSP allies to:

- Bring forward a Member's Debate
- Hold a lunchtime meeting where people with ME could tell their story
- Sponsor a stand in the parliament for three days during a particular week.

5. **The wider public who may benefit from information about ME and post infectious illnesses which cause PEM**

We will raise awareness in this audience through publicity on the various issues highlighted in this strategy document. Media stories, where possible, will include the significant impact of ME on quality of life, the stories of people with severe ME, and the need for immediate government and NHS funding for specialist care.



Millions Missing - September 2022

One of the key objectives of Millions Missing is to raise awareness of the people with ME missing from society and their previous lives, and to demand support for the ME community.

As mentioned in the preceding section, this year Millions Missing will take place in two parts, with the May event focussing on empowering the advocacy community. In September, we hope to come together in person for a rally that targets MSPs, the Scottish Government and the wider public to demand change for people with ME in Scotland. The September event will depend on how safe and reasonable it is to do this at the time.

Campaigning for effective support for people with ME

We see campaigning as a vital way to reach politicians and healthcare professionals to communicate to them the urgent need to address healthcare inequalities and to provide effective support for adults, children and young people with ME.

We have identified a number of key issues for our advocacy activities in 2022. These represent the areas that the ME community has expressed support for and we feel we can make an impact in over the next 12 months. While we will focus on these core areas, we will continue to campaign on other relevant issues as they emerge during the year.

Implementation of a Scottish guideline on ME

The 2021 NICE guideline on ME/CFS potentially transforms the care that people with ME can expect to receive. Crucially, there is a specific recommendation that people with ME should not be offered graded exercise therapy (GET) or any exercise that involves fixed incremental increases in activity. Other key recommendations relate to diagnosis and specific guidelines for those with severe ME and children and young people.

The guideline does not apply automatically in Scotland and #MEAction Scotland and other organisations campaigned in 2021 to get the Scottish Government to adapt the new guideline for implementation in Scotland. As a result of the campaign, the Clinical Priorities Unit commissioned independent consultations to “gather the views of a wide range of stakeholders about the new NICE guidelines and understand which short-term priorities should be explored, and what actions should be taken, to put these guidelines into practice in Scotland”. These consultations are being carried out in February 2022, with a report due in March.

We will continue to work with the Clinical Priorities Unit in the Scottish Government on the following issues:

- Urgent publication of a Scottish guideline on ME
- Implementation of the guideline by health and social care professionals



- Removal of GET as treatment in Scotland
- Increased accessibility to, and investment in, care using the tiered service model as recommended in the Healthcare Needs Assessment (HCNA) published in 2010 and updated in 2021.

(Note: this list will be reviewed once the Scottish guideline is published.)

As noted in the previous section on awareness raising, we will enhance our lobbying by continuing to work with MSPs to raise the profile of ME in Parliament.

Education of health and social care professionals

The new guideline will require health and social care professionals to change the way they treat and support ME patients, which will need considerable education and training. The HCNA makes recommendations for education packages for medical professionals and students, and training for healthcare staff and care providers.

We will continue to campaign for the development of healthcare education about ME from NHS Education for Scotland (NES), as recommended in the HCNA. As part of the implementation of the NICE guideline in Scotland, we will be asking for ring-fenced funding for education and training programmes for GPs, medical, nursing and allied healthcare professionals. In addition, we will ask that health boards are issued with clear directions on the need to implement this education and training as a priority.

Investment in biomedical research

Biomedical research into ME has been significantly underfunded for many years, both in the UK and overseas. In Scotland in 2020, the figure was approximately £1 per patient per year - the comparable UK figure is £80 per patient per year for multiple sclerosis, a condition in which patients have a better median quality of life than people with ME.⁴ Under-investment in research has resulted in a lack of knowledge about the causes and mechanisms of ME, a lack of diagnostic markers, and no effective treatments.

The Scottish Government has provided funding for three research projects in the past 15 years:

- 2007-2011: Funded the PACE trial through the Scottish Chief Scientist Office (CSO), consisting of £250,000 for the PACE trial research and £165,055 to NHS Lothian for 'Excess Treatment costs.' The evidence from the trial, which led to the recommendation of GET and cognitive behavioural therapy (CBT) being used as treatments for ME, was deemed as 'poor/very poor' by the independent committee which wrote the NICE 2021 guideline on ME/CFS.

⁴ Hvidberg, M (2015) The Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) *Plos One*, 2015 Jul 6;10(7):e0132421. Available from: doi: 10.1371/journal.pone.0132421.



- 2018: £45,000 for a three-year PhD project, with the shortfall made up by charity Action for ME. While this funding is welcomed, it is less than £1 per patient per year.
- 2020: Funded the James Lind Alliance to help set up a Priority Setting Partnership to identify the top 10 research priorities for ME/CFS. This work is due to be completed by mid 2022. The HCNA stated that the priorities identified by this work would be critical in informing the recommendation that the Chief Scientist Office develop a new research strategy for ME/CFS.

We will campaign for:

- A commitment to investing in a sustained programme of biomedical research by the Scottish Chief Scientist's Office and other relevant bodies, which is proportional to the disease burden. The priorities of the Priority Setting Partnership should form the basis of the research programme.
 - The development of a research strategy aimed at improving the quality of research and broadening the evidence base for ME, as recommended in the HCNA.
 - Long COVID research to consider and include direct comparison to ME where the symptoms overlap, such as including non-COVID triggered ME as a control group, to benefit both patient groups.
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