

# A Very Successful Count ME In Campaign!



The 2023 ME Association Count ME In Campaign

14 September 2023

# Count ME In

## Campaign Summary

September 2023

**THANK YOU** for supporting the ME Association's (MEA's) recent Count ME In campaign.

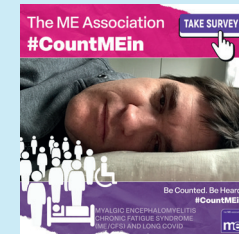
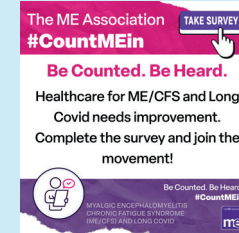
Your participation helped to make it the biggest and most successful national campaign that we have ever done. It was an ambitious project – we have learned a great deal – and we will apply this knowledge to future campaigns.

**Count ME In** was a short and unique campaign that launched 22 May and closed 31 July 2023. It was aimed at people living in the UK, Channel Islands, and Isle of Man, who thought they might be affected by symptoms – or who had a diagnosis – of ME/CFS or Long Covid.

It was the first time that we had engaged a marketing agency and market research team to position external advertising, ensuring that key messages and information were shared as widely as possible. As a result, we were able to reach more people than ever before!

We ran promotions nationally through targeted digital advertising and podcasts with the marketing agency and internally through the charity's own website, magazines, social media, and newsletter.

These promotions raised awareness of ME/CFS and Long Covid, provided information, let those affected know they were not alone, and asked those who were able to complete a short survey that focused on their health and social care experiences. The response to the campaign was fantastic!



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### External Promotions.

Total campaign impacts: 2,746,672!

- Podcasts: 773,538
- Google search ads: 34,911
- Social media ads: 1,932,267
- Email related-clicks: 5,956

Total impressions: 5,851,216!

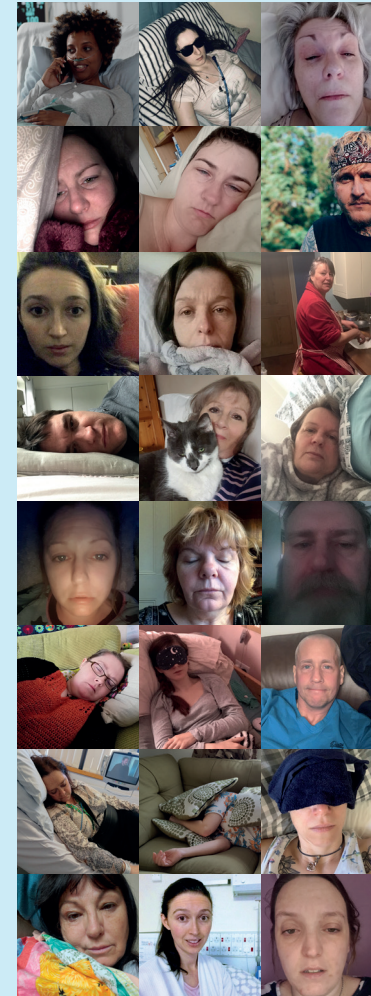
- Podcasts, Google, Social media: 2,740,716
- Email sends: 3,110,500

*N.B. Campaign impacts = total number of people who saw or listened to promotions. Impressions = total number of times the promotions appeared.*

We had more people complete the survey than have ever completed a charity survey before! The results will be analysed by an independent research team – and we will publish their full report early in 2024 – but we are keen to share some of the headline results with you today.

### YOU CAN READ THE INITIAL SURVEY RESULTS ON PAGE 5

Your participation has meant that we are able to better understand your experiences with ME/CFS and Long Covid and can be more effective in trying to improve health and social care in the months and years ahead.



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### What will we do with the survey results?

In line with the MEA's strategic vision, mission and objectives, we will focus our efforts in the following 3 areas:

#### Supporting the Patient Community:

We are responding to the Department of Health and Social Care (DHSC) Interim Delivery Plan consultation and will be using the survey results to support the submission by highlighting:

- The disparity in waiting times for a diagnosis between ME/CFS and Long Covid.
- The lack of awareness of the NICE Guidelines among healthcare professionals.
- Areas of the country where people have received good services, to act as a benchmark for:
- Areas of the country where service provision is inadequate or non-existent.

#### Educate and Influence the Medical Community:

We are currently discussing the survey results with academics and researchers. Our aim is to publish a full and independent report early in 2024 and to highlight the main findings in a medical journal. We will then consider a targeted medical campaign in 2024 to try and bring positive change to the NHS and social care services. This we hope will be helped by the publication of the final ME/CFS Delivery Plan by the DHSC.

#### Feedback:

If you have any comments about the Count ME In campaign or about the initial survey findings, do please let us know: [feedback@meassociation.org.uk](mailto:feedback@meassociation.org.uk)



## Initial Survey Results.

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### 1. 7,303 people completed the Count ME In survey:

- a. 85% (6,208 people) had a diagnosis of ME/CFS.
- b. 10% (730) had a diagnosis of Long Covid.
- c. 5% (365 people) were undiagnosed but experienced the 4 core symptoms of ME/CFS.

### 2. Some of the main findings:

- a. **Those diagnosed with ME/CFS:** 58% experienced a moderate impact (reduced mobility, all activities limited) and 19% a severe or very severe impact that increased with age. 64% had to wait over a year for a diagnosis.
- b. **Those diagnosed with Long Covid:** 57% experienced a moderate impact. This increased with age but not to the same extent as ME/CFS. 56% were diagnosed within 6 months.
- c. **Those with ME/CFS symptoms but no diagnosis:** Experienced less of an impact from their symptoms than those with a diagnosis, although this also increased with age. 11% suffered a severe or very severe impact. Top barriers to getting a diagnosis were being diagnosed with a different condition and not being referred to specialists by GPs.

- d. **Symptom management** tended to revolve around changes in behaviour such as resting more, pacing, doing less to conserve energy, and trying supplements and vitamins.
- e. **NHS Experience:**  
In general, experiences with the NHS were more likely to be rated poor than good and were worse for ME/CFS than Long Covid:
  - Only 8% of those with ME/CFS rated the NHS as good or excellent, and with Long Covid it was 15%.
  - Top barriers to good care were long waiting times, not being listened to or believed, and ineffective treatments.
  - Every region in the UK scored badly. More than 50% of regions received a very poor or poor opinion. Wales, Northern Ireland, West Midlands, Southeast England, and Scotland received over 65%.
  - There are many barriers to receiving a timely diagnosis – the main ones being that people were diagnosed with a different condition, not being referred to specialists by GPs, long waits for tests or referrals, and not being taken seriously.

- The majority of people we surveyed have experienced a lack of responsiveness from the NHS with few feeling adequately supported. Many experienced limited help and scepticism from health professionals about their condition.
- Findings strongly suggest the need for better understanding and training of healthcare providers, increased support for patients, and proper recognition and acknowledgement of ME/CFS and Long Covid by the NHS.

f. **Social Care:**

- Relatively few - 10% of those with ME/CFS and 7% of those with Long Covid - received social care support.
- Those that did were most likely to have had a successful care needs assessment, adaptations made to their home, or been provided with disability aids.
- Those with ME/CFS were less satisfied with social care provision than with NHS specialist services. 27% said they had a good or excellent experience.
- Those with Long Covid reported excellent support and communication but there were significant challenges. 38% said they had a good or excellent experience.

g. **NHS ME/CFS Specialist services and Long Covid clinics:**

- Experiences were more positive, with 47% of those with ME/CFS and 51% of those with Long Covid having used a hospital based service. Overall, 42% felt the service provided was good or excellent.

■ Those diagnosed in the last few years were likely to have received support from a specialist service for information and/or a diagnosis. However, many people that have lived with ME/CFS for longer did not receive ANY NHS support at all.

■ Not having a specialist service in their area was the top reason for not using an NHS referral service: 29% of those with ME/CFS that hadn't used a specialist service said it was because there wasn't one nearby, and 21% of those with Long Covid said it was because there wasn't a local clinic.

h. **The NICE Guidelines:**

- Results indicate that there hasn't been any noticeable improvement in NHS or social care support or service provision since publication of the NICE Guideline on ME/CFS or the Long Covid Rapid Guideline in 2021.

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- 72% of those with ME/CFS were aware of the NICE Guideline, but 65% stated they had not noticed a difference in healthcare support.
- 35% of those with Long Covid were aware of the NICE Rapid Guideline, but 66% stated that they had not noticed a difference in healthcare support.
- People with a diagnosis reported having to inform and educate their healthcare providers about the Guideline recommendations, and that there is much work still to be done if we are to see an overall improvement in healthcare support.
- There are no specific guidelines for professionals to follow and there is a lack of empathy and understanding about how great an impact ME/CFS and Long Covid can have on day-to-day activities.



- The top recommendations to improve the NICE Guidelines were:
  - Specific guidance for healthcare professionals to enable practical application of the recommendations.
  - Clarity about the fluctuating nature of ME/CFS and Long Covid and the impact on a persons ability to engage in activities of daily living.
  - Empathy: introduce 'lived experiences' to the Guidelines so that professionals can better understand the impact of these medical conditions and the need to tailor care accordingly.
  - Introduce a wider range of symptoms and a better understanding of how ME/CFS and Long Covid can interplay with other conditions such as allergies and the impact these medical conditions can have on mental health.

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### About the Count ME In survey

Findings relate to the Count Me In Survey, which was carried out by the ME Association and One Minute to Midnight (May-July 2023).

The Count Me In survey was an online survey of 7,303 people with suspected ME/CFS or Long Covid; or with a diagnosis of ME/CFS or Long Covid.

The survey respondents were a self-selected sample of people from MEA mailing lists, charity members, and from charity media platforms and from those that accessed the survey from digital advertising.

A full and independent report is being discussed and will hopefully be available in Spring 2024.

**SUPPORT FROM NHS**

ME/CFS

Only 8% said that the support they have received from the NHS for ME/CFS has been good or excellent. This is slightly higher in SW and NE England.

Overall opinion of NHS support for ME/CFS:

■ Very poor ■ Poor ■ Mixed ■ Good ■ Excellent



Col%	South West England	North East England	East Midlands	North West England	Yorkshire /Humber	East of England	London	Scotland	South East England	West Midlands	Northern Ireland	Wales
<b>Good + Excellent</b>	11%	10%	9%	9%	9%	7%	7%	7%	6%	5%	4%	4%
<b>Mixed</b>	34%	33%	33%	30%	35%	30%	32%	24%	27%	25%	13%	27%
<b>Poor + Very poor</b>	55%	56%	58%	61%	56%	62%	60%	67%	67%	69%	82%	69%

Q15: What is your overall experience of the NHS in regard to having ME/CFS?  
 Base: Used NHS help for ME/CFS (5,337)

**SUPPORT FROM NHS**

**LONG COVID**

Long Covid NHS care is perceived to be better than ME/CFS care.  
 Those in the East and South East of England were most satisfied with the NHS.

Overall opinion of NHS support for Long Covid:

Very poor Poor Mixed Good Excellent



Col%	East of England	South East England	East Midlands	North West England	Yorkshire /Humber	West Midlands	South West England	Scotland	London
<b>Good + Excellent</b>	24%	21%	16%	15%	14%	13%	13%	12%	12%
<b>Mixed</b>	43%	39%	35%	44%	45%	30%	54%	22%	36%
<b>Poor + Very poor</b>	33%	39%	49%	37%	41%	57%	33%	66%	53%

Q15: What is your overall experience of the NHS in regard to having Long Covid?  
 Base: Used NHS help for Long Covid (648). Regions with a maximum base size of 30 are shown.

**SUPPORT FROM SPECIALIST SERVICES**

ME/CFS

Satisfaction with sepcialist services is higher than for the NHS overall. 42% said they had a good or excellent experience. This is highest in Yorkshire/NW and lowest in Wales.

Overall opinion of NHS support for ME/CFS:

Very poor Poor Mixed Good Excellent



Co/%	Yorkshire /Humber	North West England	Scotland	East of England	North East England	South West England	East Midlands	South East England	London	West Midlands	Wales
<b>Good + Excellent</b>	51%	45%	43%	43%	43%	42%	41%	41%	40%	36%	35%
<b>Mixed</b>	30%	31%	27%	30%	36%	36%	35%	34%	30%	39%	40%
<b>Poor + Very poor</b>	17%	23%	26%	25%	19%	20%	21%	23%	28%	23%	28%

Q15: What is you overall experience of the ME/CFS specialist service?  
 Base: Used specialist service for ME/CFS (2,918)

**SUPPORT FROM SPECIALIST SERVICES**

**LONG COVID**

Satisfaction with specialist services is higher than for the NHS overall. 42% said they had a good or excellent experience. This is highest in Yorkshire/NW and lowest in Wales.

Overall opinion of NHS support for Long Covid:

■ Very poor ■ Poor ■ Mixed ■ Good ■ Excellent



Col%	East of England	North West England	South East England	South West England	Yorkshire /Humber	London	East Midlands
<b>Good + Excellent</b>	<b>62%</b>	<b>59%</b>	42%	40%	33%	33%	27%
<b>Mixed</b>	33%	24%	33%	37%	36%	33%	41%
<b>Poor + Very poor</b>	5%	16%	21%	17%	<b>27%</b>	<b>33%</b>	<b>27%</b>

Q15: What is your overall experience of this Long Covid clinic?

Base: Used a Long Covid clinic (364)