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Myalgic encephalomyelitis/chronic fatigue syndrome: An In-depth Analysis of Symptoms, Co-existing Conditions, and Service Utilization

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Myalgic encephalomyelitis/chronic fatigue syndrome: An In-depth Analysis of Symptoms, Co-existing Conditions, and Service Utilization

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Abstract

Objectives: This study aims to provide an in-depth analysis of the symptoms, co-existing conditions, and service utilisation among people with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Long COVID. The major research questions include the clustering of symptoms, the relationship between key factors and diagnosis time, and the perceived impact of NICE guidelines on patient care.

Design: Cross-sectional survey using secondary data analysis.

Setting: Community-based primary care level across the UK, incorporating online survey participation.

Participants: A total of 10,458 individuals responded to the survey, of which 8,804 confirmed that they or a close friend/family member had ME/CFS or Long COVID. The majority of respondents were female (83.4%), with participants from diverse regions of the UK.

Interventions: Not applicable.

Primary and Secondary Outcome Measures: Primary outcomes included prevalence and clustering of symptoms, time to diagnosis, and participant satisfaction with NHS care, while secondary outcomes focused on symptom management strategies and the perceived effect of NICE guidelines.

Results: Fatigue, post-exertional malaise, cognitive dysfunction, pain, and sleep disturbances were the most commonly reported symptoms for both conditions, with notable clustering differences between ME/CFS and Long COVID. Comorbidities were found to increase diagnosis time for ME/CFS but not for Long COVID. Despite updated NICE guidelines, no significant improvement in time to diagnosis or satisfaction with NHS care was observed.

Conclusions: ME/CFS and Long COVID share overlapping but distinct symptom clusters, indicating common challenges in management. The findings highlight significant delays in diagnosis and low satisfaction with specialist services, suggesting a need for improved self-management resources and better-coordinated care across the NHS.

Introduction

ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome) is a serious, complex, and systemic disease associated with neurological, immunological, autonomic, and energy metabolism dysfunction [1]. The World Health Organization classified it in ICD-10 G93.3 as a disease of the central nervous system [2]. Diagnostic criteria for ME/CFS in the 2021 NICE guideline state that four key symptoms must be present: debilitating fatigue that is made worse by activity, cognitive dysfunction (brain fog), unrefreshing sleep and sleep disturbance, and post-exertional malaise (PEM) [3]. At present, there is no effective treatment for ME/CFS, partly due to a lack of understanding of the underlying disease process. Therefore, management aims to reduce symptoms where possible and pacing physical and mental activities to avoid PEM [3].

Similarly, after acute COVID-19, approximately 10% of patients remain unwell for months with persistent fatigue, cognitive problems, headaches, disrupted sleep, myalgias, and arthralgias, post-exertional malaise, orthostatic intolerance, and other symptoms affecting functioning, with those more severely affected being housebound and disabled [4]. Long COVID (also known as post-COVID-19 condition) is a heterogeneous illness that follows acute infection with the SARS-COV-2 virus, which persists for three months or more after a COVID-19 infection. Common symptoms of Long COVID include fatigue, cognitive dysfunction, and breathlessness, with a wide range of other symptoms that may predominate in some patients [5,6]. Evidence exists for multiple pathophysiologic mechanisms in Long COVID [7,8]. As such, Long COVID has similarities with myalgic encephalomyelitis/chronic fatigue syndrome [9]. The similarities and differences in presentation and biology have recently been described in a recent review, highlighting abnormalities of the central and autonomic nervous system, lungs, heart, vasculature, immune system, gut microbiome, energy metabolism, and redox balance [8]. Considering the impact and similarity of these diseases, the need to highlight challenges within both conditions and set out priorities for future investigation and clinical management has been emphasised [8].

The 2021 ME/CFS NICE Guideline provides key recommendations that consider current evidence. These guidelines include principles of care for people with ME/CFS, suspecting ME/CFS, advice for people with suspected ME/CFS, diagnosis, assessment, and care and support planning by an ME/CFS specialist team, information and support, safeguarding, access to care and support, supporting people with ME/CFS in work, education, and training, multidisciplinary care, managing ME/CFS, symptom management for people with ME/CFS, managing coexisting conditions, managing flare-ups in symptoms and relapse, review in primary care, training for health and social care professionals, and care for people with severe or very severe ME/CFS [3]. The guidelines highlight the absence of evidence supporting optimal care and management. Similarly, in 2021, new NICE Guidelines for COVID-19 were also developed, and an overview of the management of this condition was presented [9], although the guidance for Long COVID is less explicitly stated.

Here, we set out to describe the views and opinions of people living with ME/CFS and Long COVID within the same survey. Whereas the guidelines for children and young people (CYP) with ME/CFS have been evaluated, to date, there has been no evaluation for adults. The evaluation of 92 CYPs highlighted key areas for improvement, including lack of investigation, referral, and poor management, particularly for CYPs with severe ME/CFS who could not leave their home [10]. We report on the views of people living with ME/CFS and those in people with Long COVID in areas associated with the key recent NICE recommendations, aiming to target key areas for both future research and current clinical management.

Methods

Aims and Objectives:

To describe current practices and experiences of people with ME/CFS and with long COVID mapped to key NICE Guideline.

Objectives:

1) To describe in Long COVID and ME/CFS participants, with and without a diagnosis, key demographics, diagnosis time, symptoms, comorbidities and treatments, experiences around support from NHS and social care, and key symptom management strategies.

2) To describe symptoms and clustering of symptoms for Long COVID and ME/CFS

3) To describe the extent of the relationship of key factors relating to time to diagnosis

4) To describe the time to diagnosis in relation to the year diagnosed.

5) To determine if the NICE Guideline on ME/CFS on patients' life and the service they received since its publication in October 2021.

Design:

This is a cross-sectional survey of the current practices and experiences of people with ME/CFS and Long COVID-19. Data were anonymously collected via an online questionnaire from a community-based convenience sample. Here, we present a secondary data analysis of this anonymous data set.

Survey Methods

An online survey was open for participation between May 22nd to July 31st 2023. Eligibility was self-assessed, and the survey was available in English. People with suspected or a diagnosis of ME/CFS or long COVID were invited to participate in answering questions to understand their experiences with diagnosis, symptom management, and NHS care, as well as map out coverage and care for people in the UK and determine areas for improvement. Consent for secondary anonymous data analysis was carried out as follows. The opening page of the survey served as the participant information sheet and consent form for data to be analysed independently. Secondary data analysis was performed on the anonymous data by the University of Exeter following confirmation from the University sponsor [2023].

No formal a priori sample size calculation was performed, and the number of responses during the study period determined the sample size. However, it was estimated that approximately 1000 people would be recruited. Considering an estimated prevalence of 250-265,000 in the UK and a confidence level of 95%, 664 people would give a margin of error of 5%.

A self-selected sample of people on the ME Association https://meassociation.org.uk mailing lists and those that clicked through digital ads on relevant websites. The study aims of the project and how the results would be used were clearly stated to respondents to inform their choice to participate as follows: 1. Inform more people about ME/CFS and Long COVID to help them obtain an accurate diagnosis if needed and find the right support to improve their life quality. 2. Produce an independent report that will raise awareness and help improve the standard of healthcare by working with the NHS and social care services.

Participants could only take the survey once but were allowed to complete it in multiple sessions to accommodate fatigue for up to 3 days if they were too fatigued to complete it in one go. Participants had to confirm that they, or they were competing for a close friend/family member, had a diagnosis or symptoms of ME/CFS or Long COVID.

Variables

Data were collected on demographics, diagnosis, symptoms, comorbidities and treatments, experiences around NHS and social care support, and key symptom management strategies.

Data sources

All data were obtained via an online survey using Qualtrics. The MEA Association and One Minute to Midnight (OMTM) designed the survey in consultation with people with ME/CFS, who trialled the survey before being released. Considering feedback to minimise burden and optimise ease of use, the questionnaire was bifurcated so that participants did not progress to questions that were not relevant to them (i.e., those with Long COVID were not asked ME/CFS questions). Participants accessed the survey via a device with an internet connection (phone, computer, tablet). Names or other identifying details were not collected.

Missing data

The current study has not imputed missing data, and the number of responses at variable levels is reported in the results/Appendix.

Statistics

Descriptive analyses were conducted to characterise gender, age, diagnoses, symptoms, comorbidities, treatments, experiences of support from NHS and social care, and key symptom management strategies. These were reported as frequencies and percentages for both ME/CFS and Long COVID-19. Comparisons, when performed, were reported using χ^2 tests, independent samples median tests, or t-tests according to the variable type and were accompanied by descriptive statistics [11-13]. For the ten most frequently reported symptoms, counts of how many times each pair of symptoms were reported by a participant were calculated to obtain symptom cooccurrence matrices for ME/CFS and Long COVID. Hierarchical Clustering Analysis (HCA) was then performed using the Euclidean distance method to obtain distance matrices, with the complete agglomeration method used for clustering (default settings in the heatmap.2 function in R version 4.3.2) [14, 15]. Graph theory was applied to provide a further comprehensive analysis of symptom interactions. Symptom cooccurrence matrices were treated as adjacency matrices for undirected graphs. Nodes in these graphs represent symptoms, and edges represent co-occurrence between symptom pairs. The strength of each edge was determined by the frequency of cooccurrence, forming weighted networks for both ME/CFS and Long COVID. Key graph metrics were calculated: Degree Centrality To identify the most connected symptoms, Betweenness Centrality To determine symptoms that act as bridges within the network, and Clustering Coefficient To measure the tendency of symptoms to cluster together. Data analysis was completed using SPSS Version 29.0 (SPSS Inc., Chicago, IL), Python 3.12 with the PyCharm IDE 2024.4.1 (JetBrains), and R. Statistical significance was indicated at $p < 0.05$ [16-17].

Results:

Objective 1

Demographics

Participants: 10458 people responded to the survey. 8804 confirmed that they or a close friend/family member had a diagnosis or symptoms of ME/CFS or Long COVID. Of those linked to ME/CFS or Long COVID, 7259 responded to gender and age questions. Demographics are shown in Supplementary Table 1. 83.4% (6053) of these respondents were female, 14.9% (1077) were male, and 1.8% (129) were non-binary or preferred to self-describe.

Diagnosis time for ME/CFS: The highest number of diagnoses (1664 individuals, 22.10%) occurred 1-2 years after noticing symptoms and informing a GP, with a number (1419, 18.84%) diagnosed within 7-12 months. 1240 individuals (16.47%) received their diagnosis within 3-6 months, while 975 (12.9) were diagnosed after more than ten years. Additionally, 883 individuals (11.72%) were diagnosed within 3-4 years, with 461 (6.12%) and 388 (5.15%) individuals diagnosed within 5-6 years and less than three months, respectively. Fewer individuals were diagnosed within 7-8 years (249, 3.31) and 9-10 years (201, 2.67%), and 51 (0.68%) individuals chose not to disclose their diagnosis time.

Diagnosis time for ME/CFS

NHS experience After being diagnosed with ME/CFS, 2157 respondents (33.76%) described their experience as very poor, poor and mixed experiences were also commonly reported, with 18.39% (1175) and 25.52% (1631) of respondents, respectively. Only 338 respondents reported having good experiences (5.29%), and even fewer rated their experience as excellent (89, 1.39%) or didn't know (34, 0.53%). (Figure 1)

Specialist visit

Many respondents (1255, 43.40%) had not seen a specialist in 5 years or longer (Figure 2). 16.32% (472) were last seen 3-4 years ago, 12.07% (349) were last seen 2-6 months ago, 11.10% (321) were last seen 1-2 years ago, and 8.89% (27) were last seen in the last month. A very small percentage of respondents stated that they hadn't been seen (78, 2.70%) or didn't know (13, 0.45%).

Diagnosed Long COVID: The survey on Long COVID diagnosis revealed that a significant portion of respondents (258, 36.13%) had mixed feelings about their experience with the NHS. Furthermore, 22.13% (158) and 16.81% (120) of respondents reported very poor and poor experiences, respectively. On the positive side, 11.76% (84) of respondents reported good experiences, with 19 rating their experience as excellent (2.66%) or expressing uncertainty (8, 1.12%).

Regarding the timing of their last specialist visit (Long Covid clinic), the majority of respondents (133, 37.46%) were last seen 2-6 months ago, while 23.66% (84) were last seen in the last month. Additionally, 16.90% (60) were last seen 1-2 years ago, and 12.96%

(46) were last seen 7-11 months ago. A small fraction of respondents haven't been seen (24, 6.76%) or expressed uncertainty about their last visit (3, 0.85%).

People with ME: Figure 3 shows that nearly half of the diagnosed patients (3026, 47.6%) were seen in a hospital-based ME/CFS specialist service. NHS GPs saw most diagnosed (4758, 74.9%) and undiagnosed (177, 63.0%) patients. The ME Association was a significant source of support for both diagnosed (3497, 55.0%) and undiagnosed (77, 27.4%) patients. Many patients also sought information online (3709, 58.4% diagnosed; 183, 65.1% undiagnosed).

For people with Long COVID: Most diagnosed patients (371, 52.3%) were seen in a hospital-based Long COVID clinic. NHS GPs saw the highest number of both diagnosed (582, 82.1%) and undiagnosed (47, 61.0%) patients. A significant number of patients also sought information online (390, 55.0% diagnosed; 38, 49.4% undiagnosed) and from family and friends (260, 36.7% diagnosed; 27, 35.1% undiagnosed), Figure 3.

Social care: The highest percentage of participants with ME and Long Covid receiving care in this study were from South West England at 14.80% (1081). This is closely followed by South East England at 13.97% (1020), East of England at 10.80% (789), and Northwest England at 10.31% (753). Other regions such as Scotland, Yorkshire and the Humber, East Midlands, London, and West Midlands have percentages ranging from 6.31% to 8.52%. The regions with the lowest percentage of people are the Isle of Man, at 0.34% (25), and the Channel Islands, at 0.10% (7), Figure 4.

Impact on life: People with ME/CFS condition: Among diagnosed patients, the majority (3709, 58.04%) reported a moderate impact on their lives, followed by a mild impact (1423, 22.27%) and a severe impact (1121, 17.54%). Among undiagnosed patients, the majority reported a moderate impact (159, 55.99%), followed by a mild impact (101, 35.56%), and a severe impact (22, 7.75%). Impact of Long COVID: Among diagnosed patients, the majority (404, 56.58%) reported a moderate impact on their lives, followed by a mild impact (193, 27.03%), and a severe impact (92, 12.89%). Among undiagnosed patients, the majority also reported a moderate impact (46, 59.74%), followed by a mild impact (22, 28.57%), and a severe impact (8, 10.39%).

Management: People with ME and Long Covid use similar ~~treatment~~ strategies to manage their symptoms (Figure 5). **People with ME**: The majority of diagnosed patients reported having to reorganise their life and take things a lot easier (4939, 80.8%), rest and sleep a lot more than before (4678, 76.5%), and reduce all activities (4908, 80.2%). A significant number of diagnosed patients also reported trying to balance activities with rest (4382, 71.6%), taking vitamins or supplements (3740, 61.2%), and using self-management approaches (3958, 64.7%). Among undiagnosed patients, the majority reported having to reorganise their life and take things a lot easier (223, 79.4%), rest and sleep a lot more than before (221, 78.6%), and reduce all activities (227, 80.8%). **In people with Long Covid**, the majority of diagnosed patients also reported having to reorganise their lives and make things a lot easier (567, 83.3%), rest and sleep a lot more than before (550, 80.8%), and reduce all activities (528, 77.5%). A significant number of diagnosed patients also reported trying to balance activities with rest (465, 68.3%), taking vitamins or supplements (434, 63.7%), and using self-management approaches (433, 63.6%). Among undiagnosed patients, the majority reported having to reorganise their life and take things a lot easier (55, 71.4%), rest and sleep a lot more than before (63, 81.8%), and reduce all activities (57, 74.0%).

Management and support were reported for people with ME, with 1096 of diagnosed patients having received an assessment from an ME/CFS specialist service (20.2%) in the last two years and accessing information and support from a specialist (1092, 20.1%). However, most diagnosed patients said they had received no help from the NHS in the last 2 years (2864, 52.8%). Fewer patients received a diagnosis from a GP (754, 13.9%), an assessment from a consultant (477, 8.8%), or an assessment from a GP (495, 9.1%). However, in people with Long COVID, Most diagnosed patients received an assessment from a Long Covid clinic (405, 62.6%) in the last two years. Many diagnosed patients also received a diagnosis from a GP (392, 60.6%), and information and support from a specialist (304, 47.0%). Fewer patients received an assessment from a GP (190, 29.4%), a consultant (153, 23.6%), or information and support from a GP (81, 12.5%).

Objective 2

Symptom prevalence with ME/CFS: A total of 450 participants within the subset of those diagnosed with ME/CFS responded with information about symptom presentation (Q5 = diagnosis, Q8 = symptom) (Figure 5, top left). The ten most commonly reported symptoms with ME/CFS (starting with the most commonly reported) were Unrefreshing sleep or sleep disturbance (n = 398, 88.22%), Debilitating Fatigue / Exhaustion (n = 397, 71.11%), Brain Fog or cognitive difficulties (n = 394, 88.44%), Pain in muscles, joints, or nerves (n = 352, 87.65%), Post-Exertional Malaise (n = 320, 78.22%), Increased sensitivity to light and noise (n = 269, 58.67%), Headache (n = 264, 59.78%), Irritable-bowel-type symptoms (n = 256, 54.00%), Increased sensitivity to hot and cold temperatures (n = 253, 56.22%), and Dizziness (n = 243, 56.89%).

Symptom prevalence with LC: There was a total of 267 participants within the subset of those diagnosed with LC that responded with information about symptom presentation (Q5 = diagnosis, Q8 = symptom) (Figure 5, top right). The eleven (there were two in joint 10th position) most commonly reported symptoms with Long COVID (starting with the most commonly reported) were Debilitating Fatigue / Exhaustion (n = 189, 42.00%), Brain Fog or cognitive difficulties (n = 186, 41.33%), Pain in muscles, joints, or nerves (n = 171, 38.00%), Unrefreshing sleep or sleep disturbance (n = 165, 36.66%), Breathlessness (n = 134, 29.78%), Headache (n = 117, 26.00%), Post-Exertional Malaise (n = 109, 24.22%), Irritable-bowel-type symptoms (n = 103, 22.89%), Dizziness (n = 98, 21.78%), and Ringing in the ears (n = 84, 18.67%), and Excessive sweating when asleep (n = 84, 18.67%).

Most reported symptoms with ME/CFS or Long COVID taken together: Of the ten most prevalent symptoms for ME/CFS and Long COVID, 8 were common to both: Brain Fog, Dizziness, Fatigue, Headache, IBS, Pain in Muscles, Joints or Nerves, PEM, and Sleep Disturbances. Light/Noise Sensitivity and Temperature Sensitivity were only within the ten most common symptoms with ME/CFS, and breathlessness, Ears Ringing, and Sleep Sweats were only within the ten most common symptoms with LC.

Symptom co-occurrence network for individuals with Myalgic Encephalomyelitis (ME) (Figure 6, middle left): This network uses graph theory to visualise how symptoms reported by the survey respondents interrelate, based on their co-occurrence: Nodes represent different symptoms experienced by individuals. Edges indicate that these symptoms frequently co-occur. The thickness of an edge correlates with the frequency of co-occurrence; thicker edges mean that the symptoms appear together more often among respondents. The Network Layout is structured so that symptoms with more connections are generally positioned more centrally, suggesting they may be common or pivotal symptoms in the condition.

The network graph visually represents how different symptoms interconnect based on their co-occurrence in patient reports. Nodes in the network represent various symptoms, and edges between them indicate that these symptoms are frequently experienced together by individuals with ME. Thicker edges denote a higher frequency of co-occurrence, highlighting symptom pairs or clusters that are more commonly reported.

From this network analysis, it is evident that certain symptoms such as fatigue, pain, and brain fog not only show strong connections to many other symptoms but also feature centrally within the network. This suggests that these symptoms are particularly prevalent and might be central to the experiences of many individuals with ME. Additionally, severity analysis indicates that these symptoms are often associated with higher impact severity scores, suggesting they significantly affect patients' quality of life.

Symptom co-occurrence network for individuals with Long COVID-19 **(Figure 6, middle right)**: A symptom co-occurrence network was constructed using graph theory to understand the relationships between different symptoms of long COVID and their co-occurrence patterns.

The graph was created by treating each symptom as a node. Edges between nodes were drawn if the corresponding symptoms co-occurred in at least one individual, and the weight of each edge was proportional to the number of individuals in which both symptoms appeared together. Visualising this network provided a graphical representation of how symptoms cluster together.

Symptoms such as fatigue, brain fog, and breathlessness tend to be linked with higher severity ratings. These symptoms, represented by nodes connected with thicker edges in the network, signify common co-occurrence and a stronger impact on the individuals' health.

Associations of symptoms: For both ME/CFS and Long COVID, we explored co-occurrence (how often a participant reported both of a pair of symptoms) within the 10 most frequently reported symptoms, then used hierarchical cluster analysis to identify symptom clusters.

ME/CFS symptom clusters: There were 448 participants with a diagnosis who responded to relevant questions (Q5 = diagnosis, Q8 = symptoms) and who reported at least one of the 10 most common symptoms. There were three clear clusters of co-occurrence for ME/CFS (Figure 5, bottom left).

Cluster 1: Debilitating Fatigue / Exhaustion, Unrefreshing sleep or sleep disturbance, and 'Brain Fog' or cognitive difficulties.

Cluster 2: Post-Exertional Malaise, and Pain in muscles, joints, or nerves.

Cluster 3: Headache, Increased sensitivity to light and noise, Dizziness, Increased sensitivity to hot and cold temperatures, and irritable bowel-type symptoms.

Long COVID symptom clusters: There were 261 participants with a diagnosis who responded to relevant questions (Q5 = diagnosis, Q8 = symptoms) and who reported at least one of the 10 most common symptoms. There were three clear co-occurrence clusters with Long COVID (Figure 5, bottom right).

Cluster 1: Debilitating Fatigue / Exhaustion, 'Brain Fog' or cognitive difficulties, Pain in muscles, joints, or nerves, and Unrefreshing sleep or sleep disturbance.

Cluster 2: Ringing in the ears and Excessive sweating when asleep.

Cluster 3: Cluster 3 included Breathlessness, Headache, Post-Exertional Malaise, irritable bowel-type symptoms, and Dizziness.

Symptoms and impact of condition: We explored the relationship between the impact of the condition (ME/CFS or Long Covid) and the prevalence of symptoms within the subset of participants with a diagnosis who responded to relevant questions (Q5 = diagnosis, Q8 = symptoms, Q15b = impact severity). With both ME/CFS and Long COVID, the more prevalent a symptom was, the lower the proportion (%) of respondents with that symptom that reported "Severe" or "Very Severe Impact" of the condition, e.g., rarer symptoms are associated with more severe impact on life (Figure 7).

Objective 3

A total of 2892 cases of diagnosed ME/CFS were reported. The distribution of these cases over time is as follows: 8.89% of the cases were diagnosed in the last month. 12.07% were diagnosed 2-6 months ago. 5.08% were diagnosed 7-11 months ago. 11.10% were diagnosed 1-2 years ago. 16.32% were diagnosed 3-4 years ago. A significant proportion (43.40%) were diagnosed five years ago or longer. 2.70% of the respondents reported that they haven't been seen. 0.45% of the respondents reported not knowing when they were diagnosed.

We found that the number of co-morbidities was significantly related to time to diagnosis in people with ME/CFS, whereas this was not the case in people with Long COVID. Other factors such as age, ethnicity, and gender were not significantly related to time to diagnosis in participants with either ME/CFS or Long COVID, R< .1 and P>.05.

Objective 4

We observed similar time to diagnosis in the first 12 months and in general for those diagnosed three years before (n = 979) and after (n = 743) the 2021 NICE Guideline (Figure 8, left).

Figure 8 (right and left) shows a potential trend to faster diagnosis in the 3-, 3-6-, and 7-12-month periods after 2022, although trends were fluctuating over the reporting periods.

Objective 5

To determine the impact of the NICE Guideline on people with ME/CFS's life and the service experience since its publication in October 2021. According to this study result, 80 (10.1%) respondents from 4761 thought that the NICE Guideline's recommendations had made a positive difference to the healthcare they received, with 70 (1.5%) people noting a positive significant impact.

480 (10.1%) people from 4761 respondents thought the NICE Guideline's recommendations had made a positive difference to the healthcare they received, with 70 (1.5%) people noting a positive significant impact.

Discussion

This study reports on the largest UK survey undertaken by the MEA, which has been reporting on symptoms, diagnosis, and management for people with ME/CFS since the publication of the 2021 NICE Guideline [3]. Importantly, the survey reports on both ME/CFS and Long COVID-19. Based on the findings of this study, only a small number of 6.9% of participants with ME/CFS and 14.42% with Long COVID-19 rated their experience with the NHS as good to excellent with the remainder reporting poor, very poor or mixed experiences. Our findings suggest a need to consider how the NHS's handling of Long COVID-19 and ME/CFS could be enhanced to support people with this condition better. The data highlights the severity of the impact with both Long COVID and ME/CFS significantly impacting people's lives, with the majority of patients experiencing a moderate to severe impact, requiring them to make substantial changes to their lifestyle and daily activities. It also highlights the importance of self-management approaches and strategies [18]. Importantly, we find symptom clusters and co-occurrence of symptoms that underscore potential directions for further investigation that may help improve the time to diagnosis and provide key service requirements and associated team members for services for people with both ME/CFS and long Covid. Additionally, the survey results indicate that individuals diagnosed with ME/CFS are less likely to have recent interactions with specialists compared to those diagnosed with Long COVID-19. Our observations suggest there is a need for better access for both with possible potential for interaction of services, considering the similar symptoms, although the presentation of symptoms may differ [19]. Our findings suggest that good evidenced, key self-management information for lifestyle, activity, sleep and symptom management should be made available to benefit people with both conditions through both NHS services and online media.

According to this study, we noted for many a-difficulty in establishing a diagnosis, with the time of diagnosis for ME/CFS varying widely. The results confirmed that many people with ME/CFS are experiencing a serious and potentially harmful delay in having their diagnosis confirmed. Many individuals are diagnosed within the first two years, but a considerable number are diagnosed after more than 10 years. A larger proportion of ME/CFS cases were diagnosed 5 years ago or longer, compared to Long COVID cases, which are more recent. This is likely due to the recency of the COVID-19 pandemic. Of note, in ME/CFS, a high number of symptoms was associated with a longer time to diagnosis. This could indicate challenges in diagnosing this condition and is in line with previous observations [20]. Considering that diagnosed individuals reported accessing more services, we propose a need for research to improve precise and timely diagnosis [21].

This study demonstrated that a range of specialist services, such as the ME Association, private GPs and HCPs, online resources, and support groups, are also important in supporting patients [22]. This observation is important considering the push towards online support and the use of evidenced hybrid technologies [23]. We further observed the need for involvement across the disciplines of healthcare professionals at a time of UK shortages, as highlighted by the 2030 World Health Organisation (WHO) rehabilitation strategy [24]. The perceived lack of service provision suggests the need for innovation, as suggested by the WHO, for more use of technology and specialist training to deliver optimal care more widely [25]. This, alongside the reported use of online services, suggests that evidenced, key self-management information for lifestyle, activity, sleep and symptom management should be made available through both NHS services and online media.

The complexity of diagnosis for people living with ME/CFS has previously been highlighted. Here, we confirm the difficulty with diagnosis and found no change in the reported time to diagnosis before and after the publication of the NICE Guideline. A key finding is that the number of comorbidities that individuals presented with was a significant factor in how long participants were diagnosed. Our findings support that the complexity of presentation may be a key factor in the timely diagnosis of people with ME/CFS. This observation aligns with one in three adults now living with more than one condition, with needs not met by established services [26] and the urgent need to find new approaches to diagnose and subsequently manage people living with more than one condition and complex health conditions [27].

When considering managing complexity in health [28], we observed three distinct symptom clusters with similar co-occurrence frequency for both ME/CFS and Long COVID. For ME/CFS, Cluster 1 (Fatigue, SleepDisturb, BrainFog) included 2 of the 4 most reported symptoms for ME/CFS (range in number of reports for symptoms in Cluster 1: 320-398). The symptoms in Cluster 1 were most often reported alongside other symptoms in Cluster 1, followed by Cluster 2 and Cluster 3. Cluster 2 (PEM, PainMuscJointNerve) included 2 of the 4 most commonly reported symptoms for ME/CFS (range: 352-394). Symptoms in Cluster 2 were more often reported alongside symptoms in Cluster 1 than with each other, which occurred at a similar frequency as with symptoms in Cluster 3. Symptoms in Cluster 3 (Headache, LightNoiseSensitivity, Dizzy, TempSensitivity, IBS) were all reported less frequently than those in Cluster 1 or Cluster 2 (range 243-269). All symptoms in Cluster 3 showed similar patterns of co-occurrence, most often reported alongside symptoms in Cluster 1, followed by Cluster 2, then Cluster 3.

For Long COVID, Cluster 1 (Fatigue, Brain Fog, Pain, MuscJointNerve, Sleep Disturb) included the four most reported symptoms with Long COVID (range 165-189). The symptoms in Cluster 1 were most often reported alongside other symptoms in Cluster 1, followed by symptoms in Cluster 3, and then symptoms in Cluster 2. Cluster 2 (EarsRing, SleepSweats) included the two least commonly reported symptoms with Long COVID (both reported 84 times). Symptoms in Cluster 2 were reported at a similar low frequency with all other symptoms within the ten most reported symptoms for Long COVID. Cluster 3 (Breathless, Headache, PEM, IBS, Dizzy). All symptoms were reported at a moderate frequency out of the ten most reported symptoms (range 98-134). All symptoms in Cluster 3 showed similar patterns of co-occurrence, most often reported alongside symptoms in Cluster 1, followed by Cluster 3, then Cluster 2. Further observation through Graph theory analysis shows co-occurrence in pairs of symptoms, with some symptoms less likely to occur and the most common symptoms more likely to occur with more severe disease impact.

The results presented above provide an overview of how often pairs of symptoms co-occur with each other and potential groupings that may inform future research into precision treatments [29]. These results provide an interesting insight into how the most frequent complaints of patients relate to each other. However, it should be considered that this analysis cannot account for relationships outside of a pairwise relationship and, therefore, cannot be used to build profiles of mutually inclusive or exclusive symptom clusters, which should be a goal for future work. Indeed, the consideration alongside the coexistence of multiple conditions would be an important area for future work and highlights that management of ME/CFS may be better understood within this context [30]. Finally, and significantly, we were surprised to find that a small but notable percentage of individuals who reported a diagnosis of ME/CFS did not experience PEM, which is a key diagnostic characteristic of the condition. This observation underscores the potential challenges in using terms such as PEM. It is possible that some individuals do experience PEM but may not fully comprehend the term, or it could be that some people are misdiagnosed with ME/CFS when they have an alternative explanation for their chronic fatigue. This could be due to some doctors not being fully informed about the current criteria requiring the presence of PEM for a diagnosis of ME/CFS, or it could be that some of the older diagnostic criteria for ME/CFS do not mandate the presence of PEM.

Conclusions

ME/CFS impacts thousands of people daily. Nearly 70% of sufferers have moderate or severe symptoms requiring them to make substantial changes to their lifestyle and daily activities. A key concern was the observed very poor times for referral for diagnosis, poor diagnosis times, poor referrals to specialist services and no significant improvements since the publication of the NICE guidelines. There is a significant complexity of co-occurring conditions, which correlate to a longer time needed to reach a diagnosis. The complexity of co-occurring conditions may extend the time for a diagnosis even further, possibly further impacted by the symptom complexity and variability. A potential target to substantially improve experiences is through the current NHS and social care services, with key areas suggested as more equitable access, better-coordinated services, comprehensive provision, and support to align with NICE guidelines across all four nations and regions. There is significant overlap in the experiences of people with Long Covid and ME/CFS from symptoms to self-management, NHS care provision and access to social care. The high number of Covid outbreaks and *high numbers of people living with ME/CFS and Long Covid may present a ticking time bomb for the NHS and Social care services, and an urgent need for education of all health professionals and social care staff on the diagnosis, care and management of people with ME/CFS, especially those with severe ME/CFS.*

We observed symptom cluster associations and cooccurrences that may inform future research into more targeted interventions. Finally, we propose a number of possible areas for further research, including the need to develop diagnostic measures, measures for monitoring systems, and interventions for management. Areas that may be a focus for research could explore the specific issues faced by patients and potential solutions, particularly around diagnosis and precision management, including evidenced systems for monitoring systems and interventions for self-management of lifestyle, activity, sleep and symptom management. The range of symptom management and treatment strategies were mainly self-administered (such as changes to day-to-day life and pacing) and, whilst highlighted as helpful, did not involve access to a multidisciplinary team of health care practitioners. We propose a need to establish the UK must establish a network of specialist referral services that follow NICE guideline recommendations on both staffing and the services they provide and access to social care throughout the UK.

Strength and Limitations

There are a number of limitations associated with the current study. First, this convenience sample relied on self-confirmed eligibility and reporting and, therefore, is susceptible to the associated biases. Indeed, our sample represented a range of ages and genders: 6053 females, 1077 males, 129 non-binary, not say 3155 and from across the UK in all four nations, and this demographic is reflective of the typical demographic when considering service provision. Our UK sample is both a strength and a weakness of the study. However, it is worth noting that we overachieved our sample size estimation by recruiting a total of 8804, which provides a 1-1.5% margin of error at a 99% confidence interval. We included carers reporting for people with ME/CFS and Long COVID, which may have affected results, although sensitivity analysis did not show differences, allowing for wider inclusion of people with severe disease as included within the NICE Guideline. Finally, this survey was completed in the UK at a time of great dissatisfaction with NHS service provision, as reported in the 2023 British Social Attitudes survey [https://www.kingsfund.org.uk/insight-and-analysis/projects/public-satisfaction-with-nhs], and this should be considered alongside conclusions.

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Patient and Public Involvement

Patients and the public were actively involved in the development of this study. The survey was designed in consultation with individuals living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Long COVID, as well as with representatives from the ME Association, to ensure that the questions addressed the key concerns and experiences of those directly affected by these conditions. Feedback was gathered during the survey design phase through a pilot test, where individuals with ME/CFS trialed the survey and provided suggestions to improve its accessibility and relevance.

Authors statement:

Martine Ainsworth-Wells, Dr. Charles Shepherd, and Russell Fleming contributed to the survey design, data collection, and final draft review. Maedeh Mansoubi, Tom Richards, Phaedra Leveridge, and Helen Dawes contributed to the data analysis and drafting of the paper.

Conflict of Interest: The authors declare that they have no conflict of interest.

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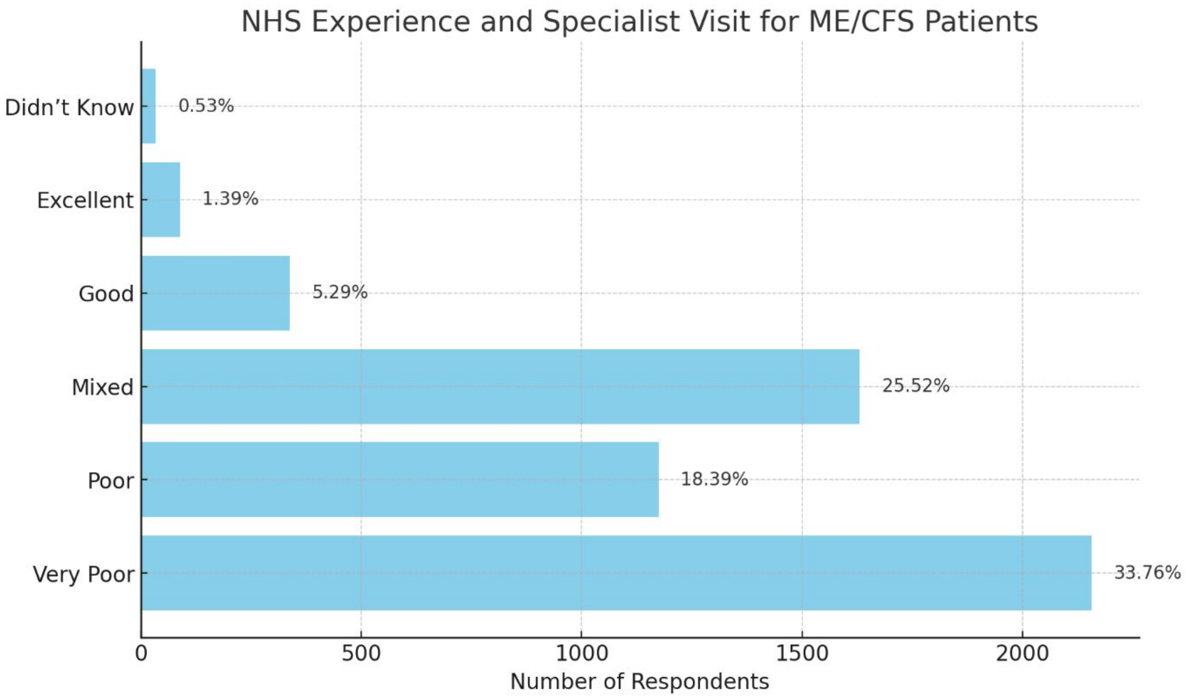

Figure 1. Responses to the question “What was your overall experience of this [Field-Specialist]?”.

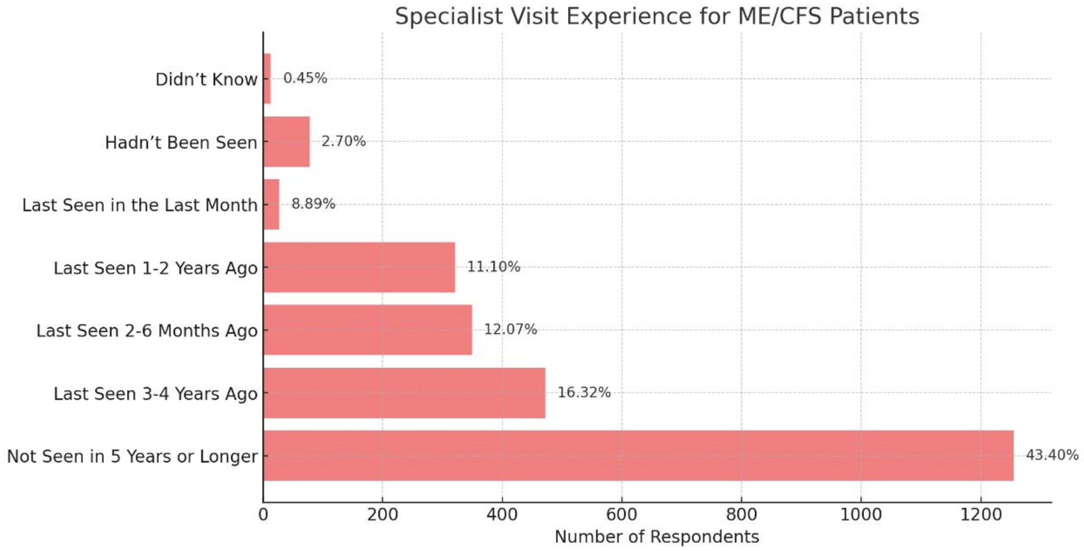

Figure 2: Responses to the question “When were you last seen by a [Field-Specialist]”?

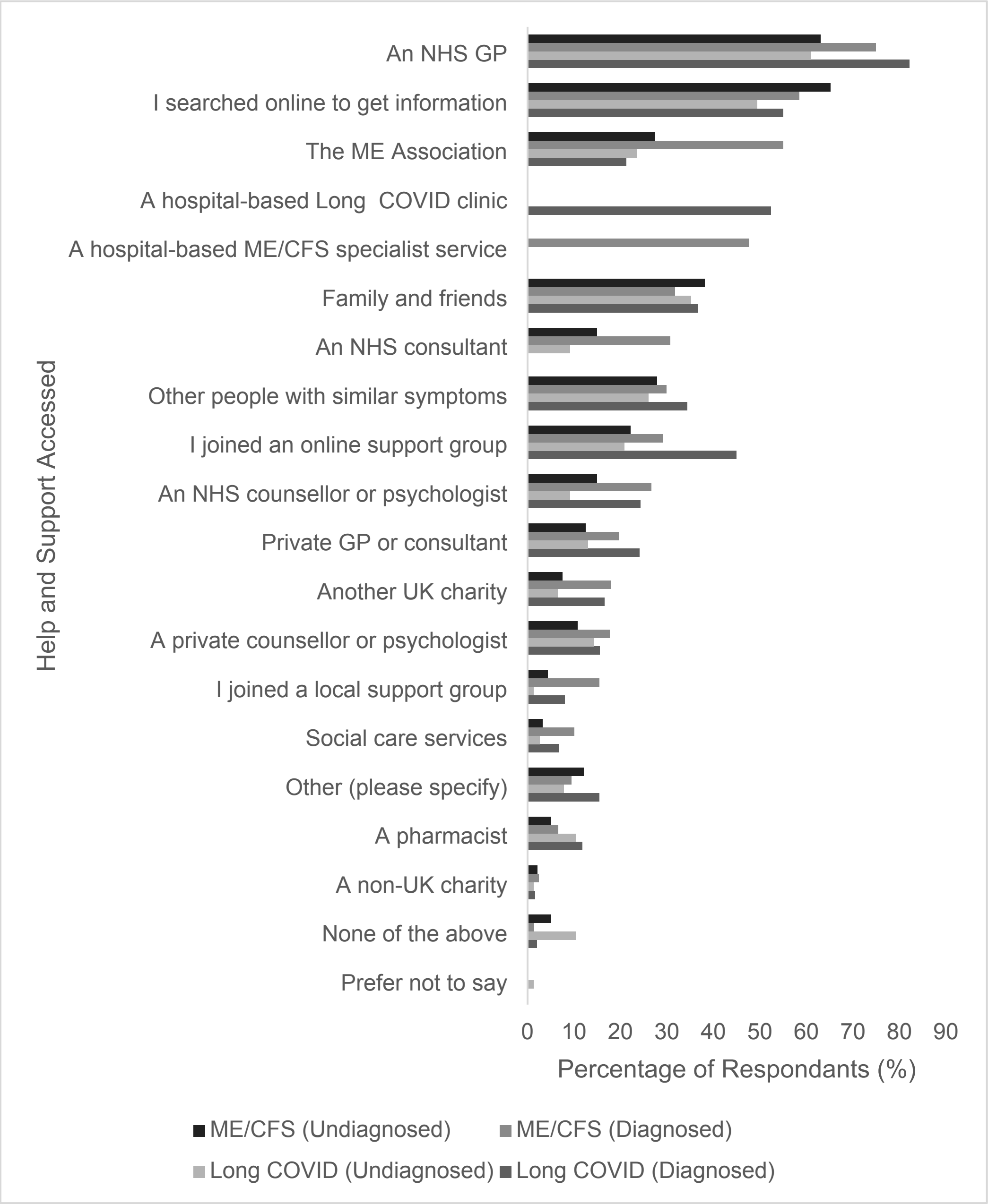

Figure 3: Support and help accessed by people with ME/CFS (diagnosed and undiagnosed) and Long Covid (diagnosed and undiagnosed). Data is presented as the percentage of respondents in each group.

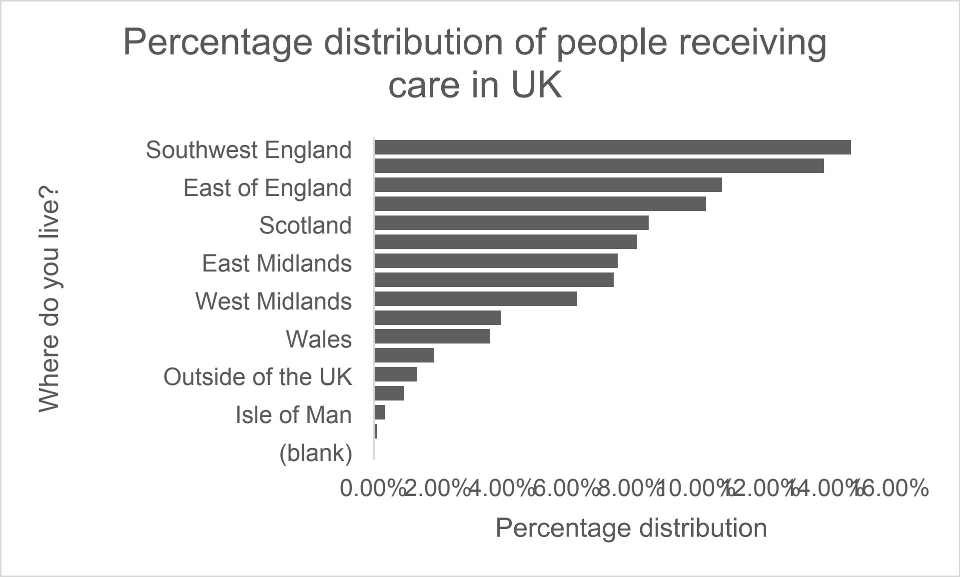

Figure 4 - Geographical distribution of people receiving care for ME

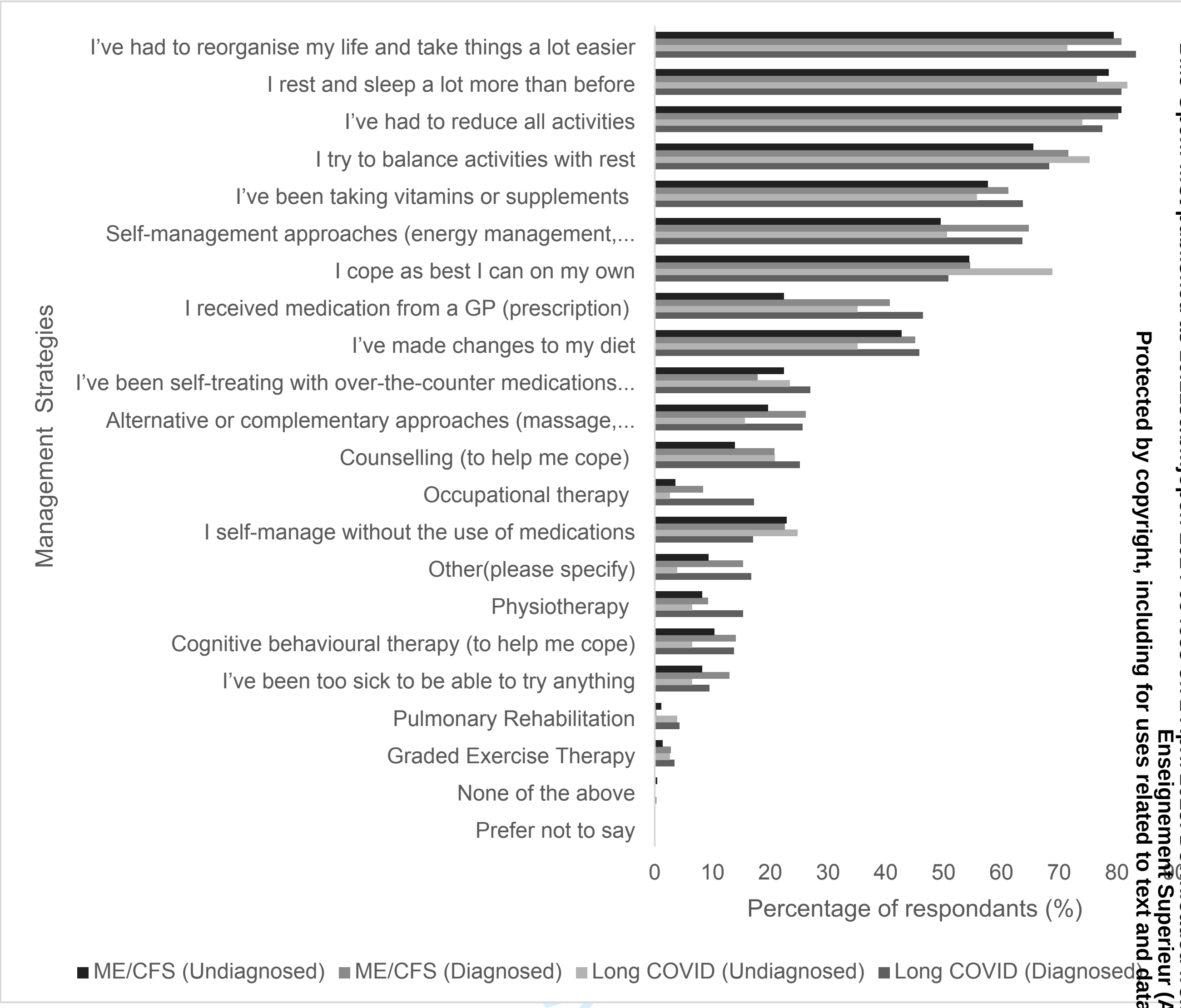

Figure 5 - Management strategies used to manage symptoms by people with ME/CFS (diagnosed and undiagnosed) and Long Covid (diagnosed and undiagnosed). Data is presented as the percentage of respondents in each group.

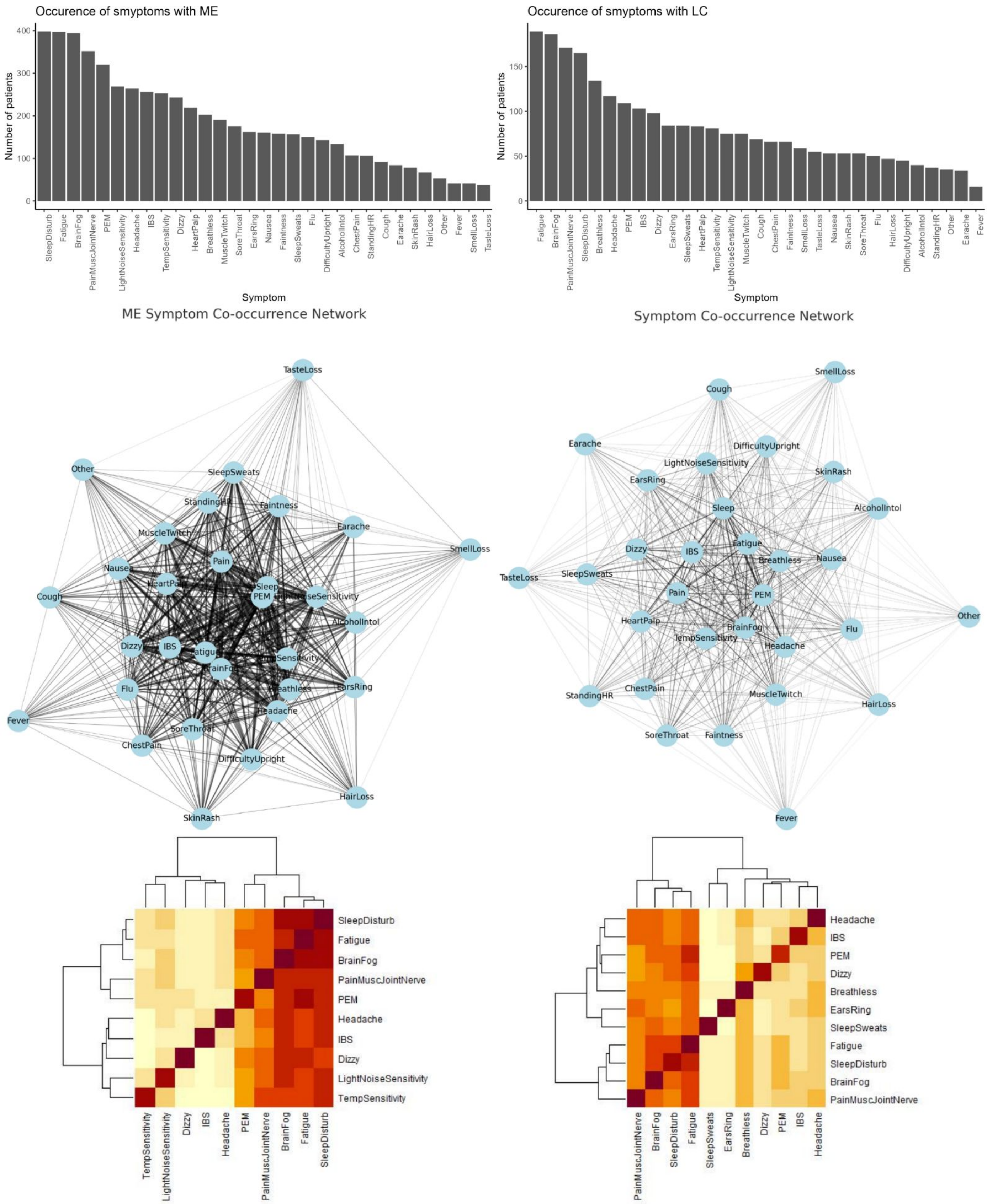

Figure 6. Occurrence of symptoms with ME/CFS (left) and Long-COVID (right). Top: Symptoms reported. Sample includes 450 participants who responded with information about symptom presentation (Q5 = diagnosis, Q8 = symptom) for

ME/CFS, and 267 for Long COVID. Middle: Graph theory for symptoms and severity of the impact. Bottom: Heatmap of co-occurrence between the 10 most commonly reported symptoms. Value on the colour scale indicates the number of times both symptoms were reported. ME/CFS, n=448; Long COVID, n=261.

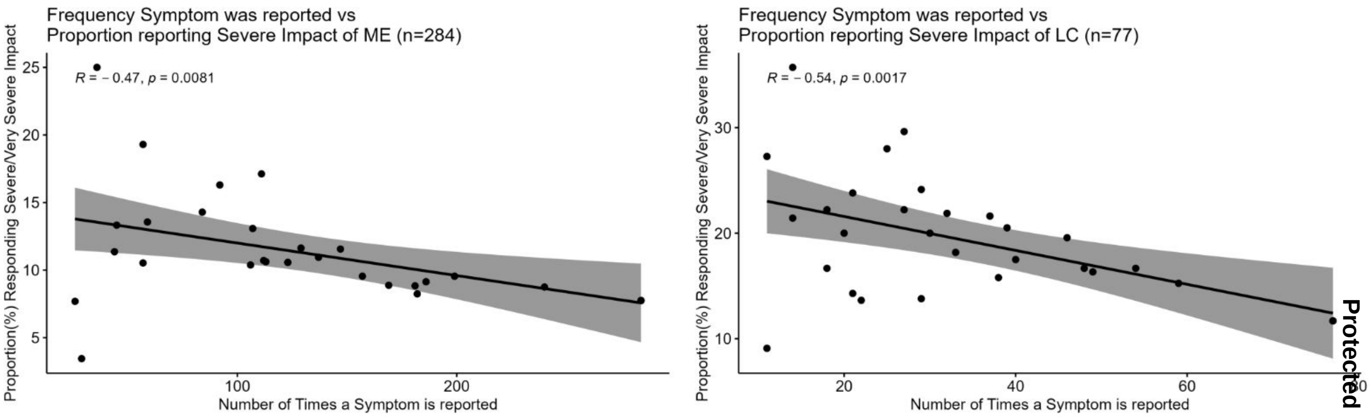

Figure 7. Correlation between prevalence of symptoms and proportion of participants who reported “Severe” impact of condition for ME/CFS (left) and Long COVID (right) using Pearson correlation coefficient.

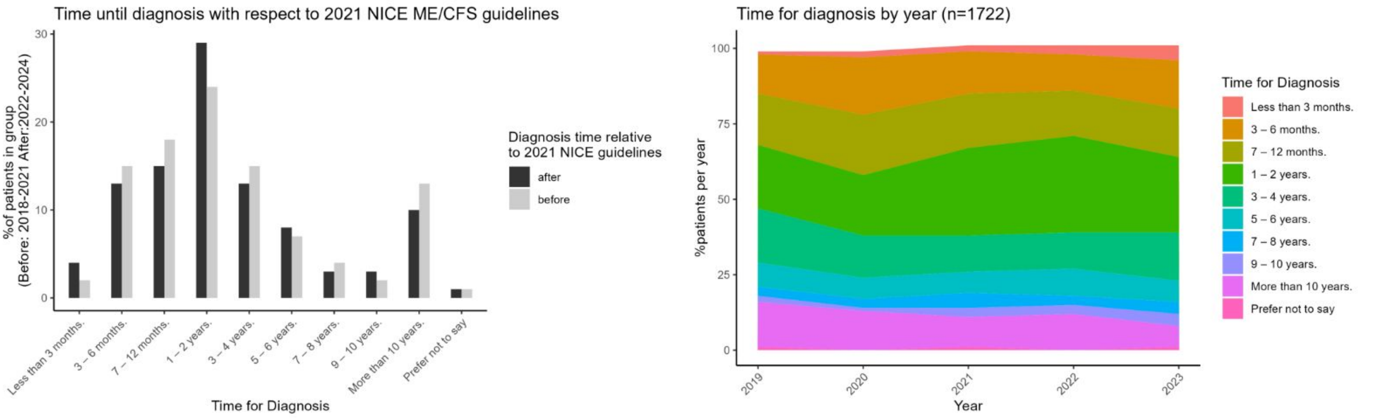

Figure 8. Time until diagnosis of ME/CFS. Left: Time until diagnosis with respect to 2021 NICE ME/CFS guidelines (before, n = 979; after n=743). Right: Time until diagnosis by Year for ME/CFS (n=1722).

Appendix

Supplementary Table 1 - Demographic data from all respondents who have, or have a family member who has, a diagnosis or symptoms of ME/CFS/Long Covid.

	Under 18	18 - 29	30 - 39	40 - 49	50 - 59	60 - 69	70 - 79	80 or older	Didn't say
Female	80	469	827	1337	1719	1118	439	49	15
Male	27	59	107	198	295	249	126	14	2
Non-Binary/ Self-described	4	43	42	23	14	3	0	0	0

Supplementary Table 2: Age and gender of people with Long Covid and ME

		Under 18	18 - 29	30 - 39	40 - 49	50 - 59	60 - 69	70 - 79	80 or older	Didn’t say
I have a close family member or friend that has been diagnosed with Long Covid	Female	9	1	4	6	4	5	1	0	0
	Male	5	1	0	2	2	2	2	1	0
	Non-binary	0	0	0	0	0	0	0	0	0
I have a close family member or friend that has been diagnosed with ME/CFS	Female	31	32	15	13	32	20	7	3	3
	Male	13	16	11	10	3	6	1	0	0
	Non-binary	2	3	0	0	0	0	0	0	0
I have a close family member or friend with symptoms of Long Covid but no diagnosis	Female	0	0	0	2	1	1	2	0	0
	Male	0	0	0	0	1	2	0	0	0
	Non-binary	0	0	0	0	0	0	0	0	0
I have a close family member or friend with symptoms of ME/CFS but no diagnosis	Female	2	0	0	1	4	4	0	1	0
	Male	0	1	0	0	0	1	1	0	0
	Non-binary	0	0	0	0	0	0	0	0	0
I have symptoms and a diagnosis of Long Covid	Female	7	27	80	150	179	74	17	3	0
	Male	2	3	14	29	37	23	9	0	0
	Non-binary	0	2	2	4	2	0	0	0	0
I have symptoms and a diagnosis of ME/CFS	Female	27	378	685	1109	1419	974	391	41	12
	Male	6	35	76	145	233	203	104	11	2
	Non-binary	2	32	36	19	12	3	0	0	0
I think I have Long Covid symptoms but have not been diagnosed	Female	1	3	7	11	16	7	12	0	0
	Male	1	0	1	1	3	6	3	2	0
	Non-binary	0	0	1	0	0	0	0	0	0
I think I have ME/CFS symptoms but have not been diagnosed	Female	3	28	36	45	64	33	9	1	0
	Male	0	3	5	11	16	6	6	0	0
	Non-binary	0	6	3	0	0	0	0	0	0

Supplementary Table 3: Time of Diagnosis

Time of diagnosis for ME/CFS	**Numbers**	**Percentage**
Less than 3 months.	388	5.15
7 – 12 months.	1419	18.84
1 – 2 years.	1664	22.1
3 – 4 years.	883	11.72
3 – 6 months.	1240	16.47
5 – 6 years.	461	6.12
7 – 8 years.	249	3.31
9 – 10 years.	201	2.67
More than 10 years.	975	12.95
Prefer not to say	51	0.68
Grand Total	**7531**	**100**

Supplementary Table 4: Ethnicity

ETHNICITY	**Number**
English/Welsh/Scottish/Northern Irish/British	6574
ANY OTHER WHITE BACKGROUND	306
IRISH	89
WOULD RATHER NOT SAY	78
ANY OTHER MIXED/MULTIPLE ETHNIC BACKGROUND	40
WHITE AND ASIAN	36
WHITE AND BLACK CARIBBEAN	34
ANY OTHER ETHNIC GROUP	33
INDIAN	31
(BLANK)	24
CARIBBEAN	9
PAKISTANI	8
ANY OTHER ASIAN BACKGROUND	8
ANY OTHER BLACK/AFRICAN/CARIBBEAN BACKGROUND	7
AFRICAN	7
WHITE AND BLACK AFRICAN	6
CHINESE	6
ARAB	3
BANGLADESHI	3
GYPSY OR IRISH TRAVELLER	1
GRAND TOTAL	**7303**

Supplementary Table 2 - Responses to the question 'To what extent [Field-Impact] [Field-RespType] impact your life today?'

Condition	**Diagnosis**		**No impact**	**Mild impact**	**Moderate impact**	**Severe impact**	**Very severe impact**	**Total**
Long COVID	Diagnosed	Count	12	193	404	92	13	714
		%	1.68	27.03	56.58	12.89	1.82	
	Undiagnosed	Count	0	22	46	8	1	77
		%	0.00	28.57	59.74	10.39	1.30	
	Both	Count	12	215	450	100	14	791
		%	1.52	27.18	56.89	12.64	1.77	
ME/CFS	Diagnosed	Count	47	1423	3709	1121	90	6390
		%	0.74	22.27	58.04	17.54	1.41	
	Undiagnosed	Count	2	101	159	22	0	284
		%	0.70	35.56	55.99	7.75	0.00	
	Both	Count	49	1524	3868	1143	90	6674
		%	0.73	22.83	57.96	17.13	1.35	

Supplementary Table 3 - Responses to the question 'Which of the following have you used to find help and support?' Count and percentages of all respondents within the group.

Support system		Long COVID			ME/CFS		
		Diagnosed	Undiagnosed	Total	Diagnosed	Undiagnosed	
A hospital-based Long COVID clinic	Count	371	0	371	0	0	0
	%	52.3	0.0	47.2	0.0	0.0	0.0
A hospital-based ME/CFS specialist service	Count	0	0	0.0	3026	0	3026
	%	0.0	0.0	0.0	47.6	0.0	45.6
An NHS consultant	Count	224	7	231.0	1950	42	1992
	%	31.6	9.1	29.4	30.7	14.9	30.0
An NHS counsellor or psychologist	Count	172	7	179.0	1690	42	1732
	%	24.3	9.1	22.8	26.6	14.9	26.1
A private counsellor or psychologist	Count	110	11	121.0	1117	30	1147
	%	15.5	14.3	15.4	17.6	10.7	17.3
An NHS GP	Count	582	47	629.0	4758	177	4935
	%	82.1	61.0	80.0	74.9	63.0	74.4
Private GP or consultant	Count	171	10	181.0	1249	35	1284
	%	24.1	13.0	23.0	19.7	12.5	19.3

A pharmacist	Count	83	8	91.0	418	14	432
	%	11.7	10.4	11.6	6.6	5.0	6.5
Social care services	Count	48	2	50.0	635	9	644
	%	6.8	2.6	6.4	10.0	3.2	9.7
The ME Association	Count	150	18	168.0	3497	77	3574
	%	21.2	23.4	21.4	55.0	27.4	53.8
Another UK charity	Count	117	5	122.0	1143	21	1164
	%	16.5	6.5	15.5	18.0	7.5	17.5
A non-UK charity	Count	11	1	12.0	153	6	159
	%	1.6	1.3	1.5	2.4	2.1	2.4
I joined an online support group	Count	318	16	334.0	1850	62	1912
	%	44.9	20.8	42.5	29.1	22.1	28.8
I joined a local support group	Count	57	1	58.0	978	12	990
	%	8.0	1.3	7.4	15.4	4.3	14.9
Other people with similar symptoms	Count	243	20	263.0	1902	78	1980
	%	34.3	26.0	33.5	29.9	27.8	29.8
Family and friends	Count	260	27	287.0	2015	107	2122
	%	36.7	35.1	36.5	31.7	38.1	32.0
I searched online to get information	Count	390	38	428.0	3709	183	3892
	%	55.0	49.4	54.5	58.4	65.1	58.6
None of the above	Count	14	8	22.0	88	14	102
	%	2.0	10.4	2.8	1.4	5.0	1.5
Other (please specify)	Count	109	6	115.0	598	34	632
	%	15.4	7.8	14.6	9.4	12.1	9.5
Prefer not to say	Count	0	1	1.0	8	0	8
	%	0.0	1.3	0.1	0.1	0.0	0.1
	Count	709	77	786	6356	281	6637

Supplementary Table 4 - Responses to the question 'What help have you received from the NHS in regard to [Field-RespType] in the last 2 years?' Count and percentages of all respondents with a diagnosis of Long COVID and ME/CFS.

		Diagnosed Long COVID	Diagnosed ME/CFS
A diagnosis from a GP	Count	392	754
	%	60.6	13.9
An assessment from a consultant	Count	153	477
	%	23.6	8.8
An assessment from a GP	Count	190	495
	%	29.4	9.1
	Count	405	0

An assessment from a long COVID clinic	%	62.6	0
An assessment from a ME/CFS specialist service	Count	0	1096
	%	0	20.2
Information and support from a Field Specialist	Count	304	1092
	%	47.0	20.1
Information and support from a consultant	Count	67	206
	%	10.4	3.8
Information and support from a GP	Count	81	267
	%	12.5	4.9
Other (please specify)	Count	68	29
	%	10.5	7.9
None of the above	Count	23	2864
	%	3.6	52.8
Prefer not to say	Count	4	6
	%	0.6	0.6
Total	Count	647	5424

Supplementary Table 5 - Responses to the question 'What is your overall experience of the NHS in regard to having [Field-RespType]?'

		Very Poor	Poor	Mixed	Good	Excellent	Don't know
Diagnosed Long COVID	Count	158	120	258	84	19	8
	%	22.13	16.81	36.13	11.76	2.66	1.12
Diagnosed ME/CFS	Count	2157	1175	1631	338	89	34
	%	33.76	18.39	25.52	5.29	1.39	0.53

Supplementary Table 6 - Responses to the question 'What help have you received from social care services in regard to [Field-RespType]?' Count and percentages of all respondents with a diagnosis of Long COVID and ME/CFS.

		Diagnosed Long COVID	Diagnosed ME/CFS
I am waiting to receive a care needs assessment	Count	5	21
	%	10.6%	3.4%
I am waiting on the outcome of a care needs assessment	Count	3	15
	%	6.4%	2.5%
I've had a care needs assessment that was successful	Count	19	330
	%	40.4%	54.0%
I've had a care needs assessment that was unsuccessful	Count	0	83
	%	0.0%	13.6%
I've been provided with equipment	Count	6	98
	%	12.8%	16.0%

I've had changes made to my home	Count	2	62
	%	4.3%	10.1%
I've been moved to sheltered accommodation	Count	0	2
	%	0.0%	0.3%
I've not been moved to sheltered accommodation	Count	1	8
	%	2.1%	1.3%
I receive a personal budget and employ a carer	Count	0	6
	%	0.0%	1.0%
I receive a personal budget and my local authority employ a carer	Count	0	1
	%	0.0%	0.2%
I've not needed changes made to my home	Count	3	2
	%	6.4%	0.3%
I need changes made to my home but haven't been offered any	Count	2	13
	%	4.3%	2.1%
I didn't think I was eligible for social care but will contact my local authority after completing this survey	Count	1	8
	%	2.1%	1.3%
I've not applied for an assessment but need social care support. I need equipment but haven't been offered any	Count	5	15
	%	10.6%	2.5%
I need equipment but haven't been offered any	Count	0	22
	%	0.0%	3.6%
Other (please specify)	Count	4	86
	%	8.5%	14.1%
None of the above	Count	1	11
	%	2.1%	1.8%
Prefer not to say	Count	0	3
	%	0.0%	0.5%
	Count	47	611

Supplementary Table 7 - Responses to the question 'You said you've used a [Field-Specialist]. Which of these apply to you in terms of the effect the service had on your health and wellbeing?' Count and percentages of all respondents with a diagnosis of Long COVID and ME/CFS.

		Diagnosed Long COVID	Diagnosed ME/CFS
I benefitted from the information, support and management recommendations	Count	159	1310
	%	43.9%	44.8%
I benefitted from the support when severely or very severely affected	Count	48	238
	%	13.3%	8.1%
	Count	211	1418
	%	58.3%	48.5%

I felt my experiences were validated and I was made comfortable			
I felt the number of appointments with the service were sufficient	Count	62	452
	%	17.1%	15.5%
I felt the service was able to tailor recommendations to meet my needs	Count	69	466
	%	19.1%	15.9%
I felt the specialist service met my expectations	Count	65	534
	%	18.0%	18.3%
I helped to create a care and support plan which was shared with my GP	Count	28	121
	%	7.7%	4.1%
I received a diagnosis	Count	177	1878
	%	48.9%	64.2%
I received a medical assessment	Count	173	1324
	%	47.8%	45.3%
I was able to access the service remotely when needed	Count	112	584
	%	30.9%	20.0%
I was able to return to the service when needed	Count	47	337
	%	13.0%	11.5%
The healthcare professionals at the service were knowledgeable and understanding	Count	186	1413
	%	51.4%	48.3%
Other (Please specify)	Count	44	473
	%	12.2%	16.2%
None of these	Count	28	240
	%	7.7%	8.2%
Total	Count	362	2924

Supplementary Table 8 - Responses to the question 'When were you last seen by a [Field-Specialist]?'

Condition	Timeframe	Count	Percentage (%)
Long COVID	In the last month	84	23.66
	2-6 months ago	133	37.46
	7-11 months ago	46	12.96
	1-2 years ago	60	16.90
	3-4 years ago	5	1.41
	5 years ago or longer	0	0.00
	I haven't been seen	24	6.76
	Don't know	3	0.85

Supplementary Table 9 - Responses to the question 'How do you manage your symptoms?' Count and percentages of all respondents within the group.

Symptom management method	Count	Long COVID			ME/CFS		
		Diagnosed	Undiagnosed	Total	Diagnosed	Undiagnosed	Total
Cognitive behavioural therapy (to help me cope)	Count	93	5	98	855	29	884
	%	13.7	6.5	12.9	14.0	10.3	13.8
Counselling (to help me cope)	Count	171	16	187	1263	39	1302
	%	25.1	20.8	24.7	20.7	13.9	20.4
Occupational therapy	Count	117	2	119	512	10	522
	%	17.2	2.6	15.7	8.4	3.6	8.2
Graded Exercise Therapy	Count	23	2	25	173	4	177
	%	3.4	2.6	3.3	2.8	1.4	2.8
Pulmonary Rehabilitation	Count	29	3	32	21	3	24
	%	4.3	3.9	4.2	0.3	1.1	0.4
Physiotherapy	Count	104	5	109	564	23	587
	%	15.3	6.5	14.4	9.2	8.2	9.2
I received medication from a GP (prescription)	Count	316	27	343	2491	63	2554
	%	46.4	35.1	45.3	40.7	22.4	39.9
I've been self-treating with over-the-counter medications (from a pharmacy)	Count	183	18	201	1088	63	1151
	%	26.9	23.4	26.5	17.8	22.4	18.0
I've been taking vitamins or supplements	Count	434	43	477	3740	162	3902
	%	63.7	55.8	62.9	61.2	57.7	61.0
I self-manage without the use of medications	Count	116	19	135	1379	64	1443
	%	17.0	24.7	17.8	22.5	22.8	22.6
I've made changes to my diet	Count	312	27	339	2757	120	2877
	%	45.8	35.1	44.7	45.1	42.7	45.0
I try to balance activities with rest	Count	465	58	523	4382	184	4566
	%	68.3	75.3	69.0	71.6	65.5	71.4
I rest and sleep a lot more than before	Count	550	63	613	4678	221	4899
	%	80.8	81.8	80.9	76.5	78.6	76.6
I've had to reduce all activities	Count	528	57	585	4908	227	5135
	%	77.5	74.0	77.2	80.2	80.8	80.3
I've had to reorganise my life and take things a lot easier	Count	567	55	622	4939	223	5162
	%	83.3	71.4	82.1	80.8	79.4	80.7
Self-management approaches (energy management, pacing etc.)	Count	433	39	472	3958	139	4097
	%	63.6	50.6	62.3	64.7	49.5	64.0
Alternative or complementary approaches (massage, reiki, homeopathy etc.)	Count	174	12	186	1595	55	1650
	%	25.6	15.6	24.5	26.1	19.6	25.8
	Count	346	53	399	3342	153	3495

I cope as best I can on my own	%	50.8	68.8	52.6	54.6	54.4	54.6
I've been too sick to be able to try anything	Count	65	5	70	787	23	810
	%	9.5	6.5	9.2	12.9	8.2	12.7
None of the above	Count	2	0	2	7	1	8
	%	0.3	0.0	0.3	0.1	0.4	0.1
Other(please specify)	Count	114	3	117	935	26	961
	%	16.7	3.9	15.4	15.3	9.3	15.0
Prefer not to say	Count	0	0	0	9	0	9
	%	0.0	0.0	0.0	0.1	0.0	0.1
	Count	681	77	758	6116	281	6397

In participants with ME/CFS, the most common co-morbidities were allergies (45.4%), chemical sensitivities (44.6%) and interstitial cystitis (42.1%).

Supplementary Table 10 - Responses to the question 'Have you been diagnosed with any of the following conditions in addition to ME / CFS?' Count and percentages of all respondents with ME/CFS, with and without a formal diagnosis

		Diagnosed	Undiagnosed	Total
Allergies	Count	2875	0	2875
	%	45.4	0.0	45.4
Anxiety	Count	789	0	789
	%	12.5	0.0	12.5
Chemical Sensitivities	Count	2822	0	2822
	%	44.6	0.0	44.5
Depression	Count	43	0	43
	%	0.7	0.0	0.7
Diabetes (type 1)	Count	389	0	389
	%	6.1	0.0	6.1
Diabetes (type 2)	Count	505	0	505
	%	8.0	0.0	8.0
Endometriosis	Count	2118	0	2118
	%	33.5	0.0	33.4
Fibromyalgia	Count	691	0	691
	%	10.9	0.0	10.9
Hypermobility Syndromes	Count	507	0	507
	%	8.0	0.0	8.0
Incontinence	Count	1198	0	1198
	%	18.9	0.0	18.9
Insomnia	Count	248	0	248
	%	3.9	0.0	3.9
Interstitial Cystitis	Count	2662	0	2662
	%	42.1	0.0	42.0
Irritable Bowel Syndrome (IBS)	Count	206	0	206
	%	3.3	0.0	3.3

Mast Cell Activation Syndrome (MCAS)	Count	1967	0	1967
	%	31.1	0.0	31.0
Migraine	Count	705	0	705
	%	11.1	0.0	11.1
Orthostatic Intolerance	Count	732	0	732
	%	11.6	0.0	11.6
Postural Orthostatic Tachycardia Syndrome (PoTS)	Count	540	0	540
	%	8.5	0.0	8.5
None of the above	Count	45	0	45
	%	0.7	0.0	0.7
Prefer not to say	Count	1759	0	1759
	%	27.8	0.0	27.8
Other (please specify)	Count	105	10	115
	%	1.7	100.0	1.8
Total respondents	Count	6327	10	6337

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Understanding Symptom Clusters, Diagnosis, and Healthcare Experiences in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Long COVID: A Cross-Sectional Survey in the UK

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Abstract

Objectives: This study aims to provide an in-depth analysis of the symptoms, co-existing conditions, and service utilisation among people with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Long COVID. The major research questions include the clustering of symptoms, the relationship between key factors and diagnosis time, and the perceived impact of NICE guidelines on patient care.

Design: Cross-sectional survey using secondary data analysis.

Setting: Community-based primary care level across the UK, incorporating online survey participation.

Participants: A total of 10,458 individuals responded to the survey, of which 8,804 confirmed that they or a close friend/family member had ME/CFS or Long COVID. The majority of respondents were female (83.4%), with participants from diverse regions of the UK.

Primary and Secondary Outcome Measures: Primary outcomes included prevalence and clustering of symptoms, time to diagnosis, and participant satisfaction with NHS care, while secondary outcomes focused on symptom management strategies and the perceived effect of NICE guidelines.

Results: Fatigue (88.2%), post-exertional malaise (78.2%), cognitive dysfunction (88.4%), pain (87.6%), and sleep disturbances (88.2%) were the most commonly reported symptoms among participants with ME/CFS, with similar patterns observed in Long COVID. Time to diagnosis for ME/CFS ranged widely, with 22.1% diagnosed within 1–2 years of symptom onset and 12.9% taking more than 10 years. Despite updated NICE guidelines, only 10.1% of participants reported a positive impact on care, and satisfaction with NHS services remained low (6.9% for ME/CFS and 14.4% for Long COVID).

Conclusions: ME/CFS and Long COVID share overlapping but distinct symptom clusters, indicating common challenges in management. The findings highlight significant delays in diagnosis and low satisfaction with specialist services, suggesting a need for improved self-management resources and better-coordinated care across the NHS.

Strengths and Limitations of this Study

- The large sample size (n = 10,458) strengthens the reliability and validity of the results.
- This project has evaluated services and management strategies for both ME and Long COVID conditions
- The online survey format facilitated participation from a geographically diverse population across the UK, ensuring broad representation.
- Reliance on self-reported diagnoses may have introduced potential bias and variability in diagnostic accuracy

Introduction

ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome) is a serious, complex, and systemic disease associated with neurological, immunological, autonomic, and energy metabolism dysfunction [1]. The World Health Organization classified it in ICD-10 G93.3 as a disease of the central nervous system [2]. Diagnostic criteria for ME/CFS in the 2021 NICE guideline state that four key symptoms must be present: debilitating fatigue that is made worse by activity, cognitive dysfunction (brain fog), unrefreshing sleep and sleep disturbance, and post-exertional malaise (PEM) [3]. At present, there is no effective treatment for ME/CFS, partly due to a lack of understanding of the underlying disease process. Therefore, management aims to reduce symptoms where possible and pacing physical and mental activities to avoid PEM [3].

Similarly, after acute COVID-19, approximately 10% of patients remain unwell for months with persistent fatigue, cognitive problems, headaches, disrupted sleep, myalgias, and arthralgias, post-exertional malaise, orthostatic intolerance, and other symptoms affecting functioning, with those more severely affected being housebound and disabled [4]. Long COVID (also known as post-COVID-19 condition) is a heterogeneous illness that follows acute infection with the SARS-COV-2 virus, which persists for three months or more after a COVID-19 infection. Common symptoms of Long COVID include fatigue, cognitive dysfunction, and breathlessness, with a wide range of other symptoms that may predominate in some patients [5,6]. Evidence exists for multiple pathophysiologic mechanisms in Long COVID [7,8]. As such, Long COVID has similarities with myalgic encephalomyelitis/chronic fatigue syndrome [9]. The similarities and differences in presentation and biology have recently been described in a recent review, highlighting abnormalities of the central and autonomic nervous system, lungs, heart, vasculature, immune system, gut microbiome, energy metabolism, and redox balance [8]. Considering the impact and similarity of these diseases, the need to highlight challenges within both conditions and set out priorities for future investigation and clinical management has been emphasised [8].

The 2021 ME/CFS NICE Guideline provides key recommendations that consider current evidence. These guidelines include principles of care for people with ME/CFS, suspecting ME/CFS, advice for people with suspected ME/CFS, diagnosis, assessment, and care and support planning by an ME/CFS specialist team, information and support, safeguarding, access to care and support, supporting people with ME/CFS in work, education, and training, multidisciplinary care, managing ME/CFS, symptom management for people with ME/CFS, managing coexisting conditions, managing flare-ups in symptoms and relapse, review in primary care, training for health and social care professionals, and care for people with severe or very severe ME/CFS [3]. The guidelines highlight the absence of evidence supporting optimal care and management. Similarly, in 2021, new NICE Guidelines for COVID-19 were also developed, and an overview of the management of this condition was presented [9], although the guidance for Long COVID is less explicitly stated.

Here, we set out to describe the views and opinions of people living with ME/CFS and Long COVID within the same survey. Whereas the guidelines for children and young people (CYP) with ME/CFS have been evaluated, to date, there has been no evaluation for adults. The evaluation of 92 CYPs highlighted key areas for improvement, including lack of investigation, referral, and poor management, particularly for CYPs with severe ME/CFS who could not leave their home [10]. We report on the views of people living with ME/CFS and those in people with Long COVID in areas associated with the key recent NICE recommendations, aiming to target key areas for both future research and current clinical management.

Methods

Aims and Objectives:

To describe current practices and experiences of people with ME/CFS and with long COVID mapped to key NICE Guideline.

Objectives:

1) To describe in Long COVID and ME/CFS participants, with and without a diagnosis, key demographics, diagnosis time, symptoms, comorbidities and treatments, experiences around support from NHS and social care, and key symptom management strategies.

2) To describe symptoms and clustering of symptoms for Long COVID and ME/CFS

3) To describe the extent of the relationship of key factors relating to time to diagnosis

4) To describe the time to diagnosis in relation to the year diagnosed.

5) To determine the impact of the NICE Guideline on ME/CFS on patients' life and the service they received since its publication in October 2021.

Design:

This is a cross-sectional survey of the current practices and experiences of people with ME/CFS and Long COVID-19.

The project used secondary data previously collected by the ME Association. As this data was gathered in accordance with the University of Exeter's ethical policy and participants consented to its use in publications, the university granted an ethical exemption for this project. Informed consent was obtained from all participants at the time of data collection, as outlined in the survey information sheet. Participants were informed about the use of their anonymised responses for research purposes, and consent was implicitly provided upon survey completion.

This study involved secondary analysis of anonymised survey data collected to explore the experiences of individuals with ME/CFS and Long COVID. The data were analysed in a secure environment in accordance with the University of Exeter's data protection policies. No new data were collected, and the secondary analysis was conducted within the scope of the original data collection purpose, as outlined to participants at the time of the survey.

Survey Methods

An online survey was open for participation between May 22nd to July 31st 2023. Eligibility was self-assessed, and the survey was available in English. People with suspected or a diagnosis of ME/CFS or long COVID were invited to participate in answering questions to understand their experiences with diagnosis, symptom management, and NHS care, as well as map out coverage and care for people in the UK and determine areas for improvement. A blank copy of the survey measure has been included as a supplementary file. Consent for secondary anonymous data analysis was carried out as follows. The opening page of the survey served as the participant information sheet and consent form for data to be analysed independently. Secondary data analysis was performed on the anonymous data by the University of Exeter following confirmation from the University sponsor [2023].

No formal a priori sample size calculation was performed, and the number of responses during the study period determined the sample size. However, it was estimated that approximately 1000 people would be recruited. Considering an estimated prevalence of 250- 265,000 in the UK and a confidence level of 95%, 664 people would give a margin of error of 5%.

A self-selected sample of people on the ME Association https://meassociation.org.uk mailing lists and those that clicked through digital ads on relevant websites. The study aims of the project and how the results would be used were clearly stated to respondents to inform their choice to participate as follows: 1. Inform more people about ME/CFS and Long COVID to help them obtain an accurate diagnosis if needed and find the right support to improve their life quality. 2. Produce an independent report that will raise awareness and help improve the standard of healthcare by working with the NHS and social care services. Participants could only take the survey once but were allowed to complete it in multiple sessions to accommodate fatigue for up to 3 days if they were too fatigued to complete it in one go. Participants had to confirm whether they were completing for themself or for a close friend/family member had a diagnosis or symptoms of ME/CFS or Long COVID. For respondents without a formal diagnosis, the survey asked them to confirm the presence of four key symptoms (fatigue, post-exertional malaise, cognitive dysfunction, and unrefreshing sleep) and their persistence for at least three months, as outlined in the NICE guidelines. For those reporting a current diagnosis, no specific question was included to confirm adherence to NICE or other diagnostic criteria.

Variables

Data were collected on demographics, diagnosis, symptoms, comorbidities and treatments, experiences around NHS and social care support, and key symptom management strategies.

Data sources

All data were obtained via an online survey using Qualtrics. The MEA Association and One Minute to Midnight (OMTM) designed the survey in consultation with people with ME/CFS, who trialled the survey before being released. Considering feedback to minimise burden and optimise ease of use, the questionnaire was bifurcated so that participants did not progress to questions that were not relevant to them (i.e., those with Long COVID were not asked ME/CFS questions). Participants accessed the survey via a device with an internet connection (phone, computer, tablet). Names or other identifying details were not collected.

Missing data

The current study has not imputed missing data, and the number of responses at variable levels is reported in the results/Appendix. Missing data were handled by incorporating all available responses for each analysis. Participants were not excluded due to incomplete survey submissions, and analyses were conducted using the maximum number of responses available for each variable. The number of respondents included in each analysis is transparently reported in the Results section.

Statistics

Descriptive analyses were conducted to characterise gender, age, diagnoses, symptoms, comorbidities, treatments, experiences of support from NHS and social care, and key symptom management strategies. These were reported as frequencies and percentages for both ME/CFS and Long COVID-19. Comparisons, when performed, were reported using χ^2 tests, independent samples median tests, or t-tests according to the variable type and were accompanied by descriptive statistics [11-13]. For the ten most frequently reported symptoms, counts of how many times each pair of symptoms were reported by a participant were calculated to obtain symptom cooccurrence matrices for ME/CFS and Long COVID. Hierarchical Clustering Analysis (HCA) was then performed using the Euclidean distance method to obtain distance matrices, with the complete agglomeration method used for clustering (default settings in the heatmap.2 function in R version 4.3.2) [14, 15]. Hierarchical clustering analysis was conducted using symptom co-occurrence matrices as input. Symptom co-occurrence matrices were constructed by calculating the frequency with which pairs of symptoms were reported together. Clustering was performed using the Euclidean distance metric to compute dissimilarities and the complete agglomeration method for grouping. Clusters were visualised using dendrograms to highlight relationships among symptoms. Graph theory was applied to provide a further comprehensive analysis of symptom interactions. For graph theory analysis, symptom co-occurrence matrices were converted into weighted, undirected graphs where nodes represented symptoms and edges indicated co-occurrences. The strength of each edge was determined by the frequency of co-occurrence. Metrics such as degree centrality (to identify the most connected symptoms), betweenness centrality (to determine symptoms acting as bridges), and clustering coefficients (to measure the tendency of symptoms to form clusters) were calculated using Python libraries. Network graphs were visualised to interpret the relationships between symptoms The strength of each edge was determined by the frequency of cooccurrence, forming weighted networks for both ME/CFS and Long COVID. Key graph metrics were calculated: Degree Centrality to identify the most connected symptoms, Betweenness Centrality To determine symptoms that act as bridges within the network, and Clustering Coefficient To measure the tendency of symptoms to cluster together. Data analysis was completed using SPSS Version 29.0 (SPSS Inc., Chicago, IL), Python 3.12 with the PyCharm IDE 2024.4.1 (JetBrains), and R. Statistical significance was indicated at p < 0.05 [16-17].

Results:

Objective 1

Demographics

Participants: 10458 people responded to the survey. 8804 confirmed that they or a close friend/family member had a diagnosis or symptoms of ME/CFS or Long COVID. Of the participants with ME/CFS or Long COVID, a subset (n = 791) reported both conditions. These cases were analysed separately to explore potential differences in symptom clustering, healthcare experiences, and self-management strategies. Of those linked to ME/CFS or Long COVID, 7259 responded to gender and age questions. The demographics for age, gender, and ethnicity are displayed in Supplementary Tables 1, 2 and 3. 83.4% (6053) of these respondents were female, 14.9% (1077) were male, and 1.8% (129) were non-binary or preferred to self-describe.

Diagnosis time for ME/CFS: The highest number of diagnoses (1664 individuals, 22.10%) occurred 1-2 years after noticing symptoms and informing a GP, with a number (1419, 18.84%) diagnosed within 7-12 months. 1240 individuals (16.47%) received their diagnosis within 3-6 months, while 975 (12.9) were diagnosed after more than ten years. Additionally, 883 individuals (11.72%) were diagnosed within 3-4 years, with 461 (6.12%) and 388 (5.15%) individuals diagnosed within 5-6 years and less than three months, respectively. Fewer individuals were diagnosed within 7-8 years (249, 3.31) and 9-10 years (201, 2.67%), and 51 (0.68%) individuals chose not to disclose their diagnosis time (Supplementary table 4).

NHS Experience after being diagnosed

NHS experience After being diagnosed with ME/CFS, 2157 respondents (33.76%) described their experience as very poor, poor and mixed experiences were also commonly reported, with 18.39% (1175) and 25.52% (1631) of respondents, respectively. Only 338 respondents reported having good experiences (5.29%), and even fewer rated their experience as excellent (89, 1.39%) or didn't know (34, 0.53%).

Diagnosed Long COVID: The survey on Long COVID diagnosis revealed that a significant portion of respondents (258, 36.13%) had mixed feelings about their experience with the NHS. Furthermore, 22.13% (158) and 16.81% (120) of respondents reported very poor and poor experiences, respectively. On the positive side, 11.76% (84) of respondents reported good experiences, with 19 rating their experience as excellent (2.66%) or expressing uncertainty (8, 1.12%).(Figure 1, Supplementary table 5)

Specialist visit

Many respondents (1255, 43.40%) had not seen a specialist in 5 years or longer 16.32% (472) were last seen 3-4 years ago, 12.07% (349) were last seen 2-6 months ago, 11.10% (321) were last seen 1-2 years ago, and 8.89% (27) were last seen in the last month. A very small percentage of respondents stated that they hadn't been seen (78, 2.70%) or didn't know (13, 0.45%).Regarding the timing of their last specialist visit (Long Covid clinic), the majority of respondents (133, 37.46%) were last seen 2-6 months ago, while 23.66% (84) were last seen in the last month. Additionally, 16.90% (60) were last seen 1-2 years ago, and 12.96% (46) were last seen 7-11 months ago. A small fraction of respondents haven't been seen (24, 6.76%) or expressed uncertainty about their last visit (3, 0.85%).(Supplementary table 6)

Management: People with ME and Long Covid use similar strategies to manage their symptoms (Figure 2). People with ME: The majority of diagnosed patients reported having to reorganise their life and take things a lot easier (4939, 80.8%), rest and sleep a lot more than before (4678, 76.5%), and reduce all activities (4908, 80.2%). A significant number of diagnosed patients also reported trying to balance activities with rest (4382, 71.6%), taking vitamins or supplements (3740, 61.2%), and using self-management approaches (3958, 64.7%). Among undiagnosed patients, the majority reported having to reorganise their life and take things a lot easier (223, 79.4%), rest and sleep a lot more than before (221, 78.6%), and reduce all activities (227, 80.8%). In people with Long Covid, the majority of diagnosed patients also reported having to reorganise their lives and make things a lot easier (567, 83.3%), rest and sleep a lot more than before (550, 80.8%), and reduce all activities (528, 77.5%). A significant number of diagnosed patients also reported trying to balance activities with rest (465, 68.3%), taking vitamins or supplements (434, 63.7%), and using self-management approaches (433, 63.6%). Among undiagnosed patients, the majority reported having to reorganise their life and take things a lot easier (55, 71.4%), rest and sleep a lot more than before (63, 81.8%), and reduce all activities (57, 74.0%).

Management and support were reported for people with ME, with 1096 of diagnosed patients having received an assessment from an ME/CFS specialist service (20.2%) in the last two years and accessing information and support from a specialist (1092, 20.1%). However, most diagnosed patients said they had received no help from the NHS in the last 2 years (2864, 52.8%). Fewer patients received a diagnosis from a GP (754, 13.9%), an assessment from a consultant (477, 8.8%), or an assessment from a GP (495, 9.1%). However, in people with Long COVID, Most diagnosed patients received an assessment from a Long Covid clinic (405, 62.6%) in the last two years. Many diagnosed patients also received a diagnosis from a GP (392, 60.6%) and information and support from a specialist (304, 47.0%). Fewer patients received an assessment from a GP (190, 29.4%), a consultant (153, 23.6%), or information and support from a GP (81, 12.5%). (Supplementary table 7)

People with ME: Figure 3 shows that nearly half of the diagnosed patients (3026, 47.6%) were seen in a hospital-based ME/CFS specialist service. NHS GPs saw most diagnosed (4758, 74.9%) and undiagnosed (177, 63.0%) patients. The ME Association was a significant source of support for both diagnosed (3497, 55.0%) and undiagnosed (77, 27.4%) patients. Many patients also sought information online (3709, 58.4% diagnosed; 183, 65.1% undiagnosed).

For people with Long COVID: Most diagnosed patients (371, 52.3%) were seen in a hospital-based Long COVID clinic. NHS GPs saw the highest number of both diagnosed (582, 82.1%) and undiagnosed (47, 61.0%) patients. A significant number of patients also sought information online (390, 55.0% diagnosed; 38, 49.4% undiagnosed) and from family and friends (260, 36.7% diagnosed; 27, 35.1% undiagnosed), Figure 3.

Social care: The highest percentage of participants with ME and Long Covid receiving care in this study were from South West England at 14.80% (1081). This is closely followed by South East England at 13.97% (1020), East of England at 10.80% (789), and Northwest England at 10.31% (753). Other regions such as Scotland, Yorkshire and the Humber, East Midlands, London, and West Midlands have percentages ranging from 6.31% to 8.52%. The regions with the lowest percentage of people are the Isle of Man, at 0.34% (25), and the Channel Islands, at 0.10% (7), Figure 3.

Impact on life: People with ME/CFS condition: Among diagnosed patients, the majority (3709, 58.04%) reported a moderate impact on their lives, followed by a mild impact (1423, 22.27%) and a severe impact (1121, 17.54%). Among undiagnosed patients, the majority reported a moderate impact (159, 55.99%), followed by a mild impact (101, 35.56%), and a severe impact (22, 7.75%). Impact of Long COVID: Among diagnosed patients, the majority (404, 56.58%) reported a moderate impact on their lives, followed by a mild impact (193, 27.03%) and a severe impact (92, 12.89%). Among undiagnosed patients, the majority also reported a moderate impact (46, 59.74%), followed by a mild impact (22, 28.57%) and a severe impact (8, 10.39%).

Objective 2

Symptom prevalence with ME/CFS: A total of 450 participants within the subset of those diagnosed with ME/CFS responded with information about symptom presentation (Q5 = diagnosis, Q8 = symptom) (Figure 4, Panel A). The ten most commonly reported symptoms with ME/CFS (starting with the most commonly reported) were Unrefreshing sleep or sleep disturbance (n = 398, 88.22%), Debilitating Fatigue / Exhaustion (n = 397, 71.11%), Brain Fog or cognitive difficulties (n = 394, 88.44%), Pain in muscles, joints, or nerves (n = 352, 87.65%), Post-Exertional Malaise (n = 320, 78.22%), Increased sensitivity to light and noise (n = 269, 58.67%), Headache (n = 264, 59.78%), Irritable-bowel-type symptoms (n = 256, 54.00%), Increased sensitivity to hot and cold temperatures (n = 253, 56.22%), and Dizziness (n = 243, 56.89%).

Symptom prevalence with LC: There was a total of 267 participants within the subset of those diagnosed with LC that responded with information about symptom presentation (Q5 = diagnosis, Q8 = symptom) (Figure 4, Panel A). The eleven (there were two in joint 10th position) most commonly reported symptoms with Long COVID (starting with the most commonly reported) were Debilitating Fatigue / Exhaustion (n = 189, 42.00%), Brain Fog or cognitive difficulties (n = 186, 41.33%), Pain in muscles, joints, or nerves (n = 171, 38.00%), Unrefreshing sleep or sleep disturbance (n = 165, 36.66%), Breathlessness (n = 134, 29.78%), Headache (n = 117, 26.00%), Post-Exertional Malaise (n = 109, 24.22%), Irritable-bowel-type symptoms (n = 103, 22.89%), Dizziness (n = 98, 21.78%), and Ringing in the ears (n = 84, 18.67%), and Excessive sweating when asleep (n = 84, 18.67%).

Most reported symptoms with ME/CFS or Long COVID taken together: Of the ten most prevalent symptoms for ME/CFS and Long COVID, 8 were common to both: Brain Fog, Dizziness, Fatigue, Headache, IBS, Pain in Muscles, Joints or Nerves, PEM, and Sleep Disturbances. Light/Noise Sensitivity and Temperature Sensitivity were only within the ten most common symptoms with ME/CFS, and breathlessness, Ears Ringing, and Sleep Sweats were only within the ten most common symptoms with LC.

Symptom co-occurrence network for individuals with Myalgic Encephalomyelitis (ME) (Figure 4, panel B): This network uses graph theory to visualise how symptoms reported by the survey respondents interrelate, based on their co-occurrence: Nodes represent different symptoms experienced by individuals. Edges indicate that these symptoms frequently co-occur. The thickness of an edge correlates with the frequency of co-occurrence; thicker edges mean that the symptoms appear together more often among respondents. The Network Layout is structured so that symptoms with more connections are generally positioned more centrally, suggesting they may be common or pivotal symptoms in the condition.

The network graph visually represents how different symptoms interconnect based on their co-occurrence in patient reports. Nodes in the network represent various symptoms, and edges between them indicate that these symptoms are frequently experienced together by individuals with ME. Thicker edges denote a higher frequency of co-occurrence, highlighting symptom pairs or clusters that are more commonly reported.

This network analysis shows that certain symptoms such as fatigue, pain, and brain fog not only show strong connections to many other symptoms but also feature centrally within the network. This suggests that these symptoms are particularly prevalent and might be central to the experiences of many individuals with ME. Additionally, severity analysis indicates that these symptoms are often associated with higher impact severity scores, suggesting they significantly affect patients' quality of life.

Symptom co-occurrence network for individuals with Long COVID-19 (Figure 4, Panel B): A symptom co-occurrence network was constructed using graph theory to understand the relationships between different symptoms of long COVID and their co-occurrence patterns.

The graph was created by treating each symptom as a node. Edges between nodes were drawn if the corresponding symptoms co-occurred in at least one individual, and the weight of each edge was proportional to the number of individuals in which both symptoms appeared together. Visualising this network provided a graphical representation of how symptoms cluster together.

Symptoms such as fatigue, brain fog, and breathlessness tend to be linked with higher severity ratings. These symptoms, represented by nodes connected with thicker edges in the network, signify common co-occurrence and a stronger impact on the individuals' health.

Associations of symptoms: For both ME/CFS and Long COVID, we explored co-occurrence (how often a participant reported both of a pair of symptoms) within the 10 most frequently reported symptoms, then used hierarchical cluster analysis to identify symptom clusters.

ME/CFS symptom clusters: There were 448 participants with a diagnosis who responded to relevant questions (Q5 = diagnosis, Q8 = symptoms) and who reported at least one of the 10 most common symptoms. There were three clear clusters of co-occurrence for ME/CFS (Figure 4, Panel C).

Cluster 1: Debilitating Fatigue / Exhaustion, Unrefreshing sleep or sleep disturbance, and ‘Brain Fog’ or cognitive difficulties.

Cluster 2: Post-Exertional Malaise, and Pain in muscles, joints, or nerves.

Cluster 3: Headache, Increased sensitivity to light and noise, Dizziness, Increased sensitivity to hot and cold temperatures, and irritable bowel-type symptoms.

Long COVID symptom clusters: There were 261 participants with a diagnosis who responded to relevant questions (Q5 = diagnosis, Q8 = symptoms) and who reported at least one of the 10 most common symptoms. There were three clear co-occurrence clusters with Long COVID (Figure 4, Panel C).

Cluster 1: Debilitating Fatigue / Exhaustion, ‘Brain Fog’ or cognitive difficulties, Pain in muscles, joints, or nerves, and Unrefreshing sleep or sleep disturbance.

Cluster 2: Ringing in the ears and Excessive sweating when asleep.

Cluster 3: Cluster 3 included Breathlessness, Headache, Post-Exertional Malaise, irritable bowel-type symptoms, and Dizziness.

Symptoms and impact of condition: We explored the relationship between the impact of the condition (ME/CFS or Long Covid) and the prevalence of symptoms within the subset of participants with a diagnosis who responded to relevant questions (Q5 = diagnosis, Q8 = symptoms, Q15b = impact severity). With both ME/CFS and Long COVID, the more prevalent a symptom was, the lower the proportion (%) of respondents with that symptom that reported “Severe” or “Very Severe Impact” of the condition, e.g., rarer symptoms are associated with more severe impact on life (Figure 4, Panel D).

Objective 3

A total of 2892 cases of diagnosed ME/CFS were reported. The distribution of these cases over time is as follows: 8.89% of the cases were diagnosed in the last month. 12.07% were diagnosed 2-6 months ago. 5.08% were diagnosed 7-11 months ago. 11.10% were diagnosed 1-2 years ago. 16.32% were diagnosed 3-4 years ago. A significant proportion (43.40%) were diagnosed five years ago or longer. 2.70% of the respondents reported that they haven’t been seen. 0.45% of the respondents reported not knowing when they were diagnosed.

We found that the number of co-morbidities was significantly related to time to diagnosis in people with ME/CFS, whereas this was not the case in people with Long COVID. Other factors such as age, ethnicity, and gender were not significantly related to time to diagnosis in participants with either ME/CFS or Long COVID, R< .1 and P>.05.

Objective 4

We observed similar time to diagnosis in the first 12 months and in general for those diagnosed three years before (n = 979) and after (n = 743) the 2021 NICE Guideline (Figure 5, left).

Figure 5 (right and left) shows a potential trend to faster diagnosis in the 3-, 3-6-, and 7-12-month periods after 2022, although trends were fluctuating over the reporting periods.

Objective 5

To determine the impact of the NICE Guideline on people with ME/CFS’s life and service experience since its publication in October 2021. According to this study result, 80 (10.1%) respondents from 4761 thought that the NICE Guideline's recommendations had made a positive difference to the healthcare they received, with 70 (1.5%) people noting a positive significant impact.

480 (10.1%) people from 4761 respondents thought the NICE Guideline's recommendations had made a positive difference to the healthcare they received, with 70 (1.5%) people noting a positive significant impact.

Discussion

This study reports on the largest UK survey undertaken by the MEA, which has been reporting on symptoms, diagnosis, and management for people with ME/CFS since the publication of the 2021 NICE Guideline [3]. Importantly, the survey reports on both ME/CFS and Long COVID-19. Based on the findings of this study, only a small number of 6.9% of participants with ME/CFS and 14.42% with Long COVID-19 rated their experience with the NHS as good to excellent, with the remainder reporting poor, very poor or mixed experiences. Our findings suggest a need to consider how the NHS's handling of Long COVID-19 and ME/CFS could be enhanced to support people with this condition better. The data highlights the severity of the impact of both Long COVID and ME/CFS significantly impacting people's lives, with the majority of patients experiencing a moderate to severe impact, requiring them to make substantial changes to their lifestyle and daily activities. It also highlights the importance of self-management approaches and strategies [18]. Importantly, we find symptom clusters and co-occurrences of symptoms that underscore potential directions for further investigation that may help improve the time to diagnosis and provide key service requirements and associated team members for services for people with both ME/CFS and long Covid. Additionally, the survey results indicate that individuals diagnosed with ME/CFS are less likely to have recent interactions with specialists compared to those diagnosed with Long COVID-19. Our observations suggest there is a need for better access for both with possible potential for interaction of services, considering the similar symptoms, although the presentation of symptoms may differ [19]. Our findings suggest that good evidenced, key self-management information for lifestyle, activity, sleep and symptom management should be made available to benefit people with both conditions through both NHS services and online media.

According to this study, we noted for many a-difficulty in establishing a diagnosis, with the time of diagnosis for ME/CFS varying widely. The results confirmed that many people with ME/CFS are experiencing a serious and potentially harmful delay in having their diagnosis confirmed. Many individuals are diagnosed within the first two years, but a considerable number are diagnosed after more than 10 years. A larger proportion of ME/CFS cases were diagnosed 5 years ago or longer, compared to Long COVID cases, which are more recent. This is likely due to the recent onset of the COVID-19 pandemic. Of note, in ME/CFS, a high number of symptoms was associated with a longer time to diagnosis. This could indicate challenges in diagnosing this condition and is in line with previous observations [20]. Considering that diagnosed individuals reported accessing more services, we propose a need for research to improve precise and timely diagnosis [21].

This study demonstrated that a range of specialist services, such as the ME Association, private GPs and HCPs, online resources, and support groups, are also important in supporting patients [22]. This observation is important considering the push towards online support and the use of evidence based hybrid technologies [23]. We further observed the need for involvement across the disciplines of healthcare professionals at a time of UK shortages, as highlighted by the 2030 World Health Organisation (WHO) rehabilitation strategy [24]. The perceived lack of service provision suggests the need for innovation, as suggested by the WHO, for more use of technology and specialist training to deliver optimal care more widely [25]. This, alongside the reported use of online services, suggests that evidenced, key self-management information for lifestyle, activity, sleep and symptom management should be made available through both NHS services and online media.

The complexity of diagnosis for people living with ME/CFS has previously been highlighted. Here, we confirm the difficulty with diagnosis and found no change in the reported time to diagnosis before and after the publication of the NICE Guideline. A key finding is that the number of comorbidities that individuals presented with was a significant factor in how long participants were diagnosed. Our findings support that the complexity of presentation may be a key factor in the timely diagnosis of people with ME/CFS. This observation aligns with one in three adults now living with more than one condition, with needs not met by established services [26] and the urgent need to find new approaches to diagnose and subsequently manage people living with more than one condition and complex health conditions [27].

When considering managing complexity in health [28], we observed three distinct symptom clusters with similar co-occurrence frequency for both ME/CFS and Long COVID. For ME/CFS, Cluster 1 (Fatigue, SleepDisturb, BrainFog) included 2 of the 4 most reported symptoms for ME/CFS (range in number of reports for symptoms in Cluster 1: 320-398). The symptoms in Cluster 1 were most often reported alongside other symptoms in Cluster 1, followed by Cluster 2 and Cluster 3. Cluster 2 (PEM, PainMuscJointNerve) included 2 of the 4 most commonly reported symptoms for ME/CFS (range: 352-394). Symptoms in Cluster 2 were more often reported alongside symptoms in Cluster 1 than with each other, which occurred at a similar frequency as with symptoms in Cluster 3. Symptoms in Cluster 3 (Headache, LightNoiseSensitivity, Dizzy, TempSensitivity, IBS) were all reported less frequently than those in Cluster 1 or Cluster 2 (range 243-269). All symptoms in Cluster 3 showed similar patterns of co-occurrence, most often reported alongside symptoms in Cluster 1, followed by Cluster 2, then Cluster 3.

For Long COVID, Cluster 1 (Fatigue, Brain Fog, Pain, MuscJointNerve, Sleep Disturb) included the four most reported symptoms with Long COVID (range 165-189). The symptoms in Cluster 1 were most often reported alongside other symptoms in Cluster 1, followed by symptoms in Cluster 3, and then symptoms in Cluster 2. Cluster 2 (EarsRing, SleepSweats) included the two least commonly reported symptoms with Long COVID (both reported 84 times). Symptoms in Cluster 2 were reported at a similar low frequency with all other symptoms within the ten most reported symptoms for Long COVID. Cluster 3 (Breathless, Headache, PEM, IBS, Dizzy). All symptoms were reported at a moderate frequency out of the ten most reported symptoms (range 98-134). All symptoms in Cluster 3 showed similar patterns of co-occurrence, most often reported alongside symptoms in Cluster 1, followed by Cluster 3, then Cluster 2. Further observation through Graph theory analysis shows co-occurrence in pairs of symptoms, with some symptoms less likely to occur and the most common symptoms more likely to occur with more severe disease impact.

The results presented above provide an overview of how often pairs of symptoms co-occur with each other and potential groupings that may inform future research into precision treatments [29]. These results provide an interesting insight into how the most frequent complaints of patients relate to each other. However, it should be considered that this analysis cannot account for relationships outside of a pairwise relationship and, therefore, cannot be used to build profiles of mutually inclusive or exclusive symptom clusters, which should be a goal for future work. Indeed, the consideration alongside the coexistence of multiple conditions would be an important area for future work and highlights that management of ME/CFS may be better understood within this context [30]. Finally, and significantly, we were surprised to find that a small but notable percentage of individuals who reported a diagnosis of ME/CFS did not experience PEM, which is a key diagnostic characteristic of the condition. This observation underscores the potential challenges in using terms such as PEM. It is possible that some individuals do experience PEM but may not fully comprehend the term, or it could be that some people are misdiagnosed with ME/CFS when they have an alternative explanation for their chronic fatigue. This could be due to some doctors not being fully informed about the current criteria requiring the presence of PEM for a diagnosis of ME/CFS, or it could be that some of the older diagnostic criteria for ME/CFS do not mandate the presence of PEM.

Strengths and Limitations

This study has several limitations. Firstly, the use of a convenience sample relying on self-reported eligibility and data introduces potential biases, including selection and reporting biases. Our sample may overrepresent individuals who are more engaged with patient advocacy groups or have access to online platforms, potentially excluding those with limited internet access or differing healthcare experiences. Our sample comprised 6,053 females, 1,077 males, 129 non-binary individuals, and 3,155 participants who preferred not to disclose their gender, spanning all four nations of the UK. While this demographic distribution reflects the typical population engaged with ME/CFS and Long COVID services, it may not represent the broader patient population, limiting our findings' generalisability. Additionally, the reliance on self-reported diagnoses without verification through clinical records or standardised diagnostic tools may affect the reliability of the data, as self-reported symptoms can lead to both overestimation and underestimation of disease prevalence. However, the substantial sample size of 8,804 participants enhances the study's statistical power, providing a margin of error between 1-1.5% at a 99% confidence interval. Including caregivers reporting on behalf of individuals with ME/CFS and Long COVID may have introduced variability in responses; nonetheless, sensitivity analyses indicated no significant differences, supporting the inclusion of perspectives from those with severe disease, as recognised in the NICE guidelines. The study offers a comprehensive analysis of the survey findings by utilising all available data without excluding incomplete responses. However, this approach may introduce variability, as participants who did not complete all sections of the survey may systematically differ from those who did. The distinction between ME/CFS (ICD-10 G93.31) and Long COVID (ICD-10 U09.9) is complex and may not always be clearly understood by patients or clinicians. This limitation is particularly relevant in cases of post-COVID fatigue where diagnostic ambiguity may arise. While our survey allowed participants to select multiple diagnoses, self-reporting may not capture nuances in clinical criteria, and future studies could benefit from incorporating clinician-verified diagnoses or more specific diagnostic questions to address this overlap. Finally, data collection occurred in the UK during a period of notable dissatisfaction with NHS service provision, as highlighted in the 2023 British Social Attitudes survey, which may have influenced participants' responses and should be considered when interpreting the conclusions.

Conclusions

ME/CFS impacts thousands of people daily. Nearly 70% of sufferers have moderate or severe symptoms requiring them to make substantial changes to their lifestyle and daily activities. A key concern was the observed very poor times for referral for diagnosis, poor diagnosis times, poor referrals to specialist services and no significant improvements since the publication of the NICE guidelines. There is a significant complexity of co-occurring conditions, which correlate to a longer time needed to reach a diagnosis. The complexity of co-occurring conditions may extend the time for a diagnosis even further, possibly further impacted by the symptom complexity and variability. A potential target to substantially improve experiences is through the current NHS and social care services, with key areas suggested as more equitable access, better-coordinated services, comprehensive provision, and support to align with NICE guidelines across all four nations and regions. There is significant overlap in the experiences of people with Long Covid and ME/CFS from symptoms to self-management, NHS care provision and access to social care. The high number of Covid outbreaks and *high numbers of people living with ME/CFS and Long Covid may present a ticking time bomb for the NHS and Social care services, and an urgent need for education of all health professionals and social care staff on the diagnosis, care and management of people with ME/CFS, especially those with severe ME/CFS.*

We observed symptom cluster associations and cooccurrences that may inform future research into more targeted interventions. Finally, we propose a number of possible areas for further research, including the need to develop diagnostic measures, measures for monitoring systems, and interventions for management. Areas that may be a focus for research could explore the specific issues faced by patients and potential solutions, particularly around diagnosis and precision management, including evidenced systems for monitoring systems and interventions for self-management of lifestyle, activity, sleep and symptom management. The range of symptom management and treatment strategies were mainly self-administered (such as changes to day-to-day life and pacing) and, whilst highlighted as helpful, did not involve access to a multidisciplinary team of health care practitioners. We propose a need to establish the UK must establish a network of specialist referral services that follow NICE guideline recommendations on both staffing and the services they provide and access to social care throughout the UK.

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Patient and Public Involvement

Patients and the public were actively involved in the development of this study. The survey was designed in consultation with individuals living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Long COVID, as well as with representatives from the ME Association, to ensure that the questions addressed the key concerns and experiences of those directly affected by these conditions. Feedback was gathered during the survey design phase through a pilot test, where individuals with ME/CFS trialed the survey and provided suggestions to improve its accessibility and relevance.

Authors statement:

Martine Ainsworth-Wells, Dr. Charles Shepherd, and Russell Fleming: Contributed to the survey design, data collection, and final draft review.

Maedeh Mansoubi, Tom Richards, Phaedra Leveridge, and Helen Dawes: Contributed to the data analysis and drafting of the paper.

All authors have given final approval of the version to be published and agree to be accountable for all aspects of the work, ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Martine Ainsworth-Wells serves as the guarantor of the study, accepting full responsibility for the work and/or the conduct of the study, had access to the data, and controlled the decision to publish.

Conflict of Interest: The authors declare that they have no conflict of interest.

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Figures

Figure 1. NHS Experience and Specialist Visits

This figure presents responses regarding NHS experiences and access to specialist care for individuals with ME/CFS and Long COVID. It categorises overall satisfaction with NHS services (Very Poor, Poor, Mixed, Good, Excellent) and illustrates the frequency of specialist visits, highlighting challenges in accessing specialised care.

Figure 2. Support Systems and Management Strategies
This figure summarises the various support systems accessed by individuals with ME/CFS and Long COVID, including NHS services, online support groups, and private healthcare providers. It also highlights the strategies used for symptom management, such as pacing, medication, self-management approaches, and alternative therapies.

Figure 3. Geographical Distribution of ME/CFS Patients Receiving Care

This figure maps the regional distribution of individuals receiving care for ME/CFS across the UK, identifying variations in healthcare access and the geographic concentration of patients receiving specialist services.

Figure 4. Symptom Prevalence and Co-Occurrence Patterns

This figure presents data on the occurrence and relationships of symptoms in ME/CFS and Long COVID.

Panel A: Most commonly reported symptoms for both conditions.

Panel B: Graph theory visualisation of symptom co-occurrence networks, identifying relationships between frequently reported symptoms.

Panel C: Heatmap of symptom co-occurrence, with darker shades indicating stronger associations between symptoms.

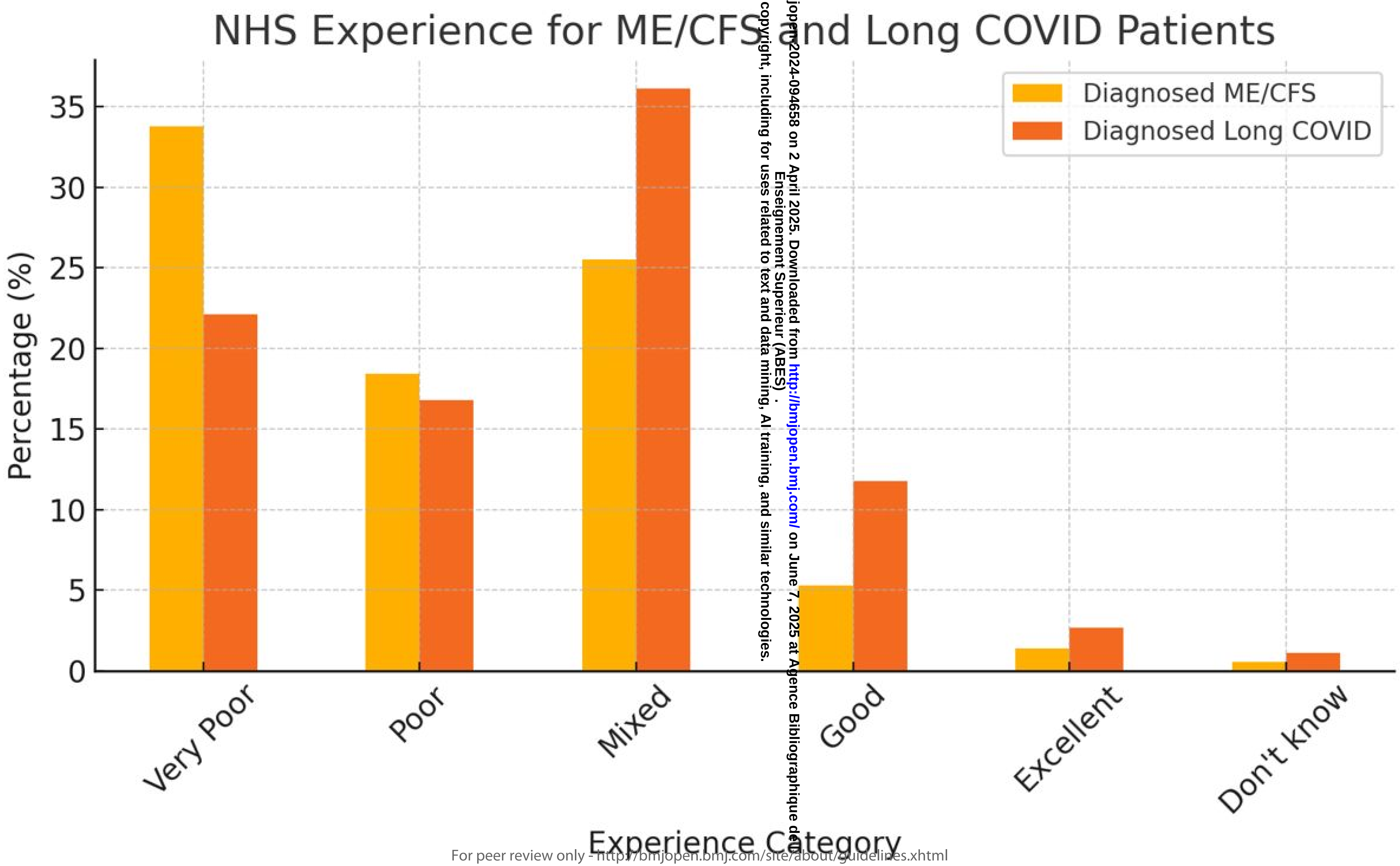
Panel D: Correlation between symptom prevalence and reported severity of impact, illustrating how certain symptoms contribute to higher levels of disability.

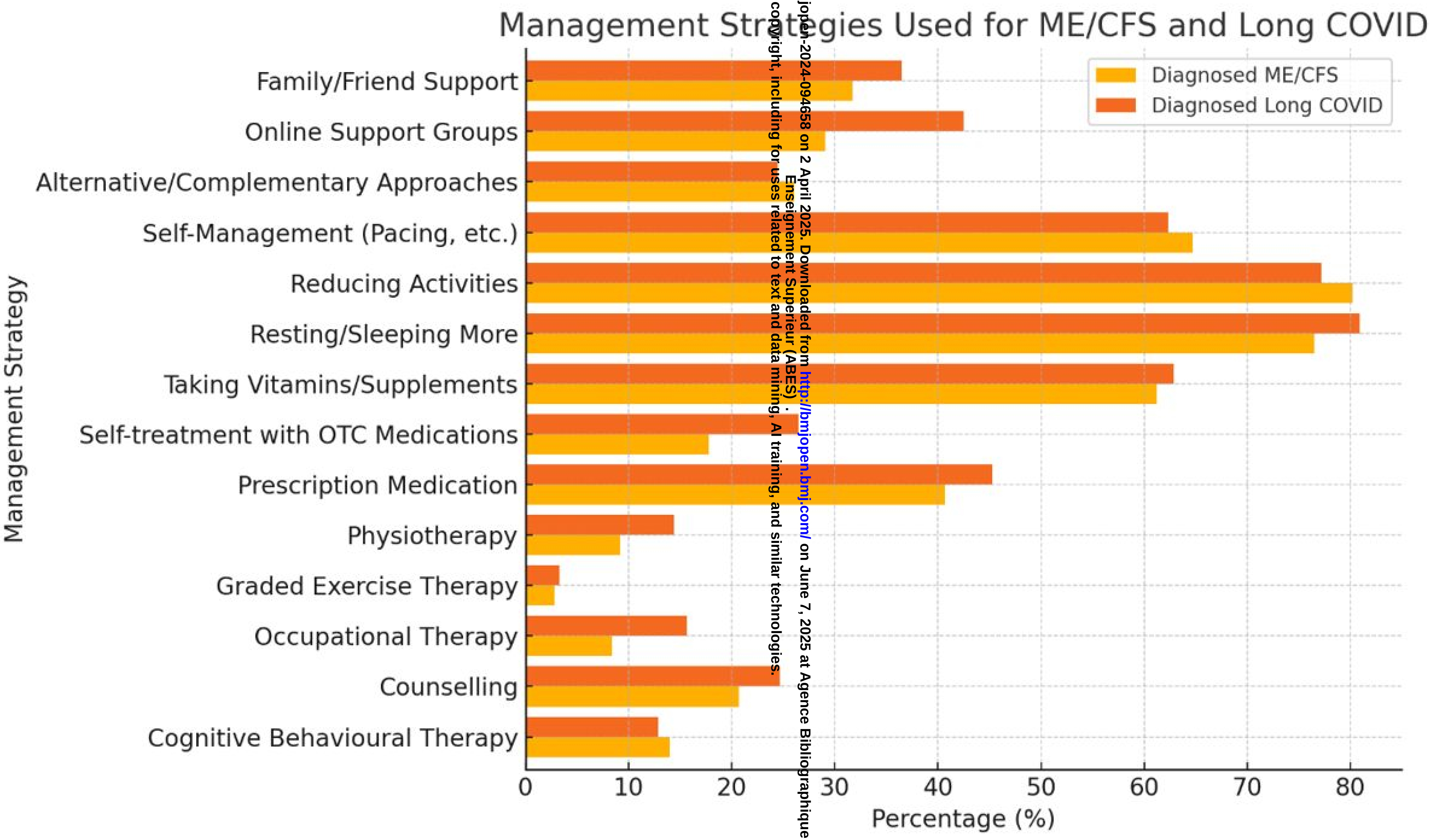
Figure 5. Time to Diagnosis for ME/CFS

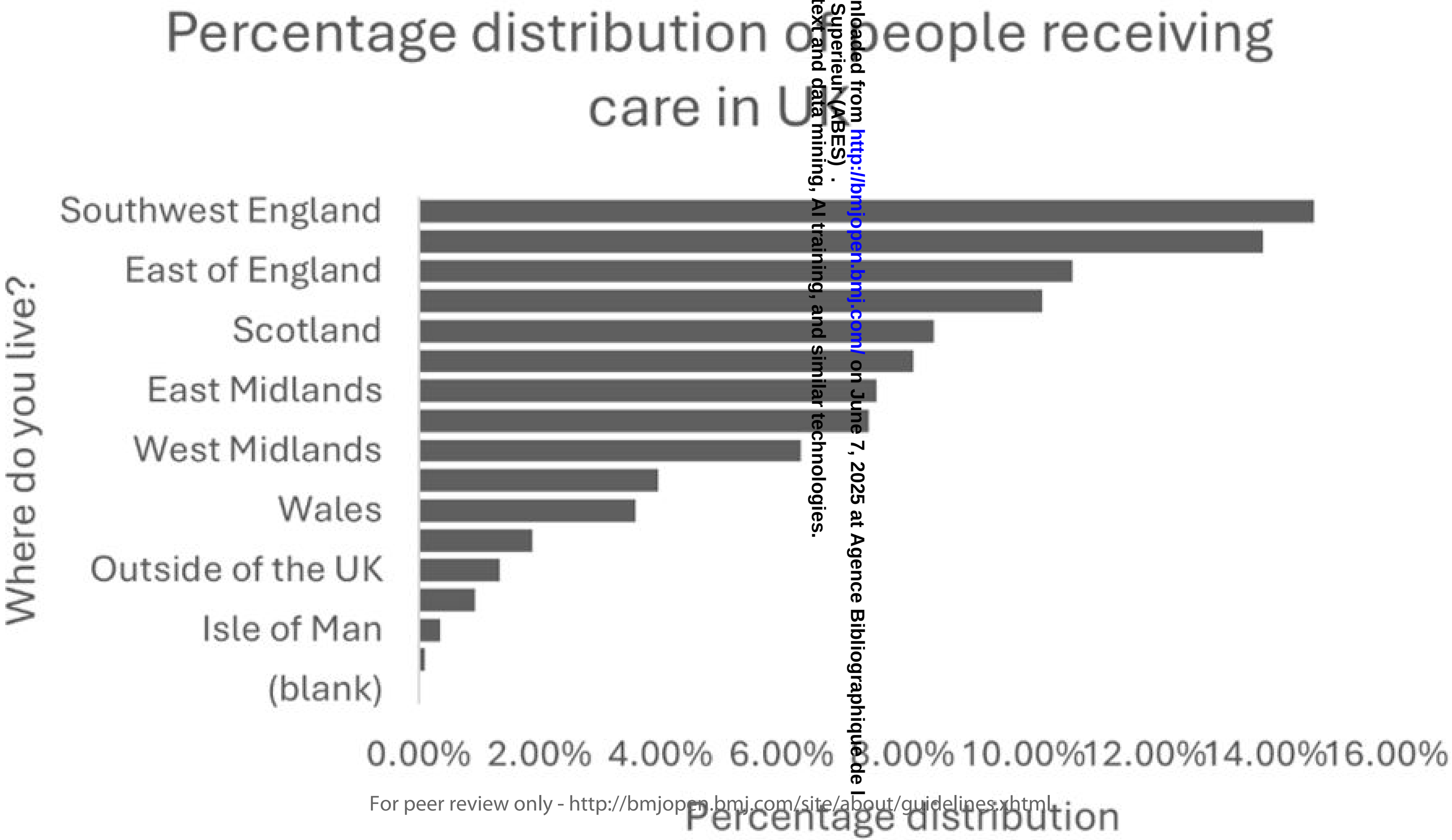
This figure explores the time taken to receive an ME/CFS diagnosis.

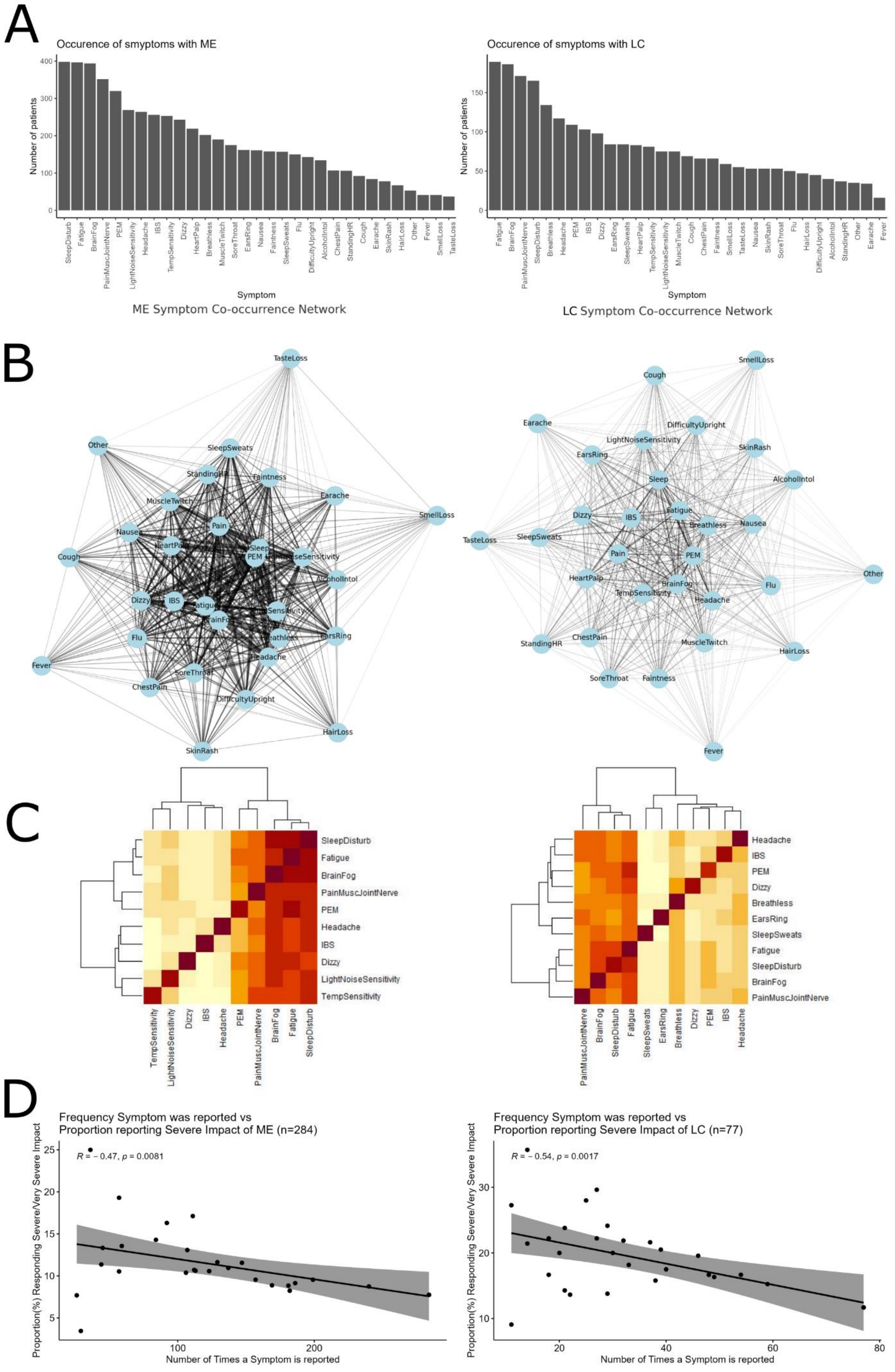
Left: Comparison of time to diagnosis before and after the 2021 NICE ME/CFS guidelines, assessing whether updated recommendations influenced diagnosis timelines.

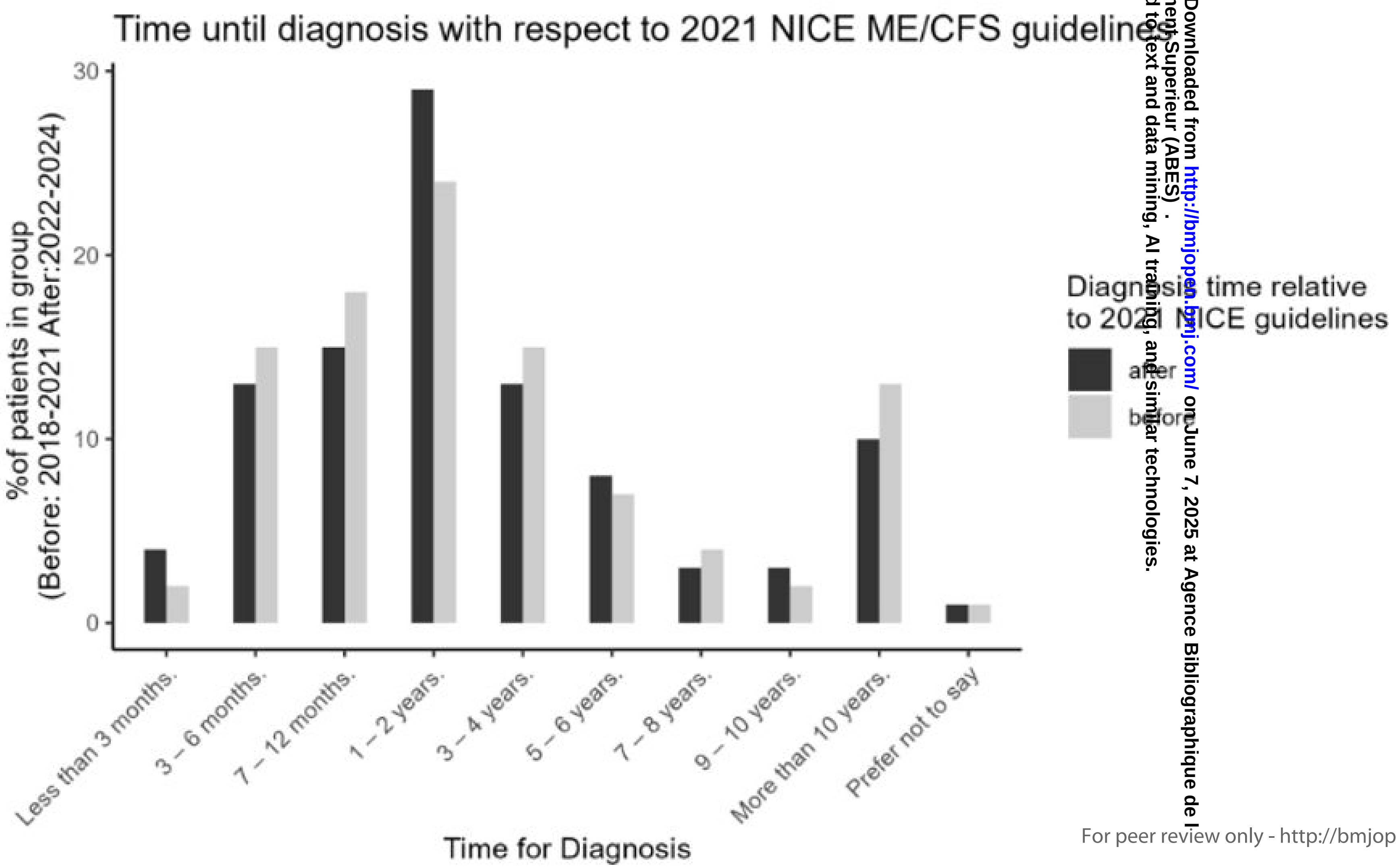
Right: Historical trend analysis of ME/CFS diagnoses over the years, showing variations in diagnosis rates and potential improvements in early detection.

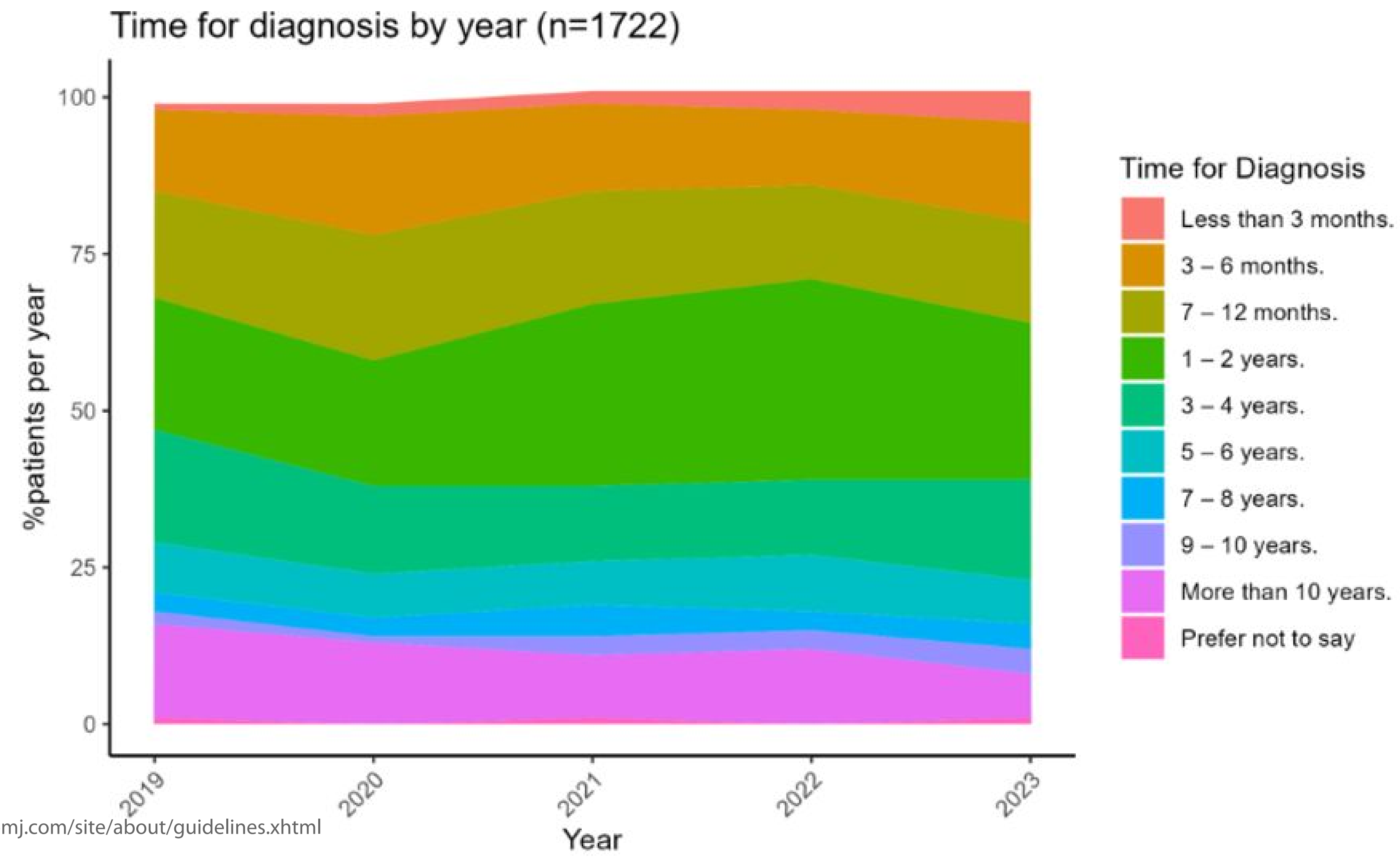

NHS Experience for ME/CFS and Long COVID Patients
Diagnosed ME/CFS
Diagnosed Long COVID
Percentage (%)
0
5
10
15
20
25
30
35
Very Poor
Poor
Mixed
Good
Excellent
Don't know
Experience Category


Management Strategies Used for ME/CFS and Long COVID
Diagnosed ME/CFS
Diagnosed Long COVID
Management Strategy
Family/Friend Support
Online Support Groups
Alternative/Complementary Approaches
Self-Management (Pacing, etc.)
Reducing Activities
Resting/Sleeping More
Taking Vitamins/Supplements
Self-treatment with OTC Medications
Prescription Medication
Physiotherapy
Graded Exercise Therapy
Occupational Therapy
Counselling
Cognitive Behavioural Therapy
0
10
20
30
40
50
60
70
80
Percentage (%)


Percentage distribution of people receiving care in UK
Where do you live?
Southwest England
East of England
Scotland
East Midlands
West Midlands
Wales
Outside of the UK
Isle of Man
(blank)
0.00%
2.00%
4.00%
6.00%
8.00%
10.00%
12.00%
14.00%
16.00%
Percentage distribution


A
Occurence of smyptoms with ME
Number of patients
Symptom
SleepDisturb
Fatigue
BrainFog
PainMuscJointNerve
PEM
LightNoiseSensitivity
Headache
IBS
TempSensitivity
Dizzy
HeartPalp
Breathless
MuscleTwitch
SoreThroat
EarsRing
Nausea
Faintness
SleepSweats
Flu
DifficultyUpright
AlcoholIntol
ChestPain
StandingHR
Cough
Earache
SkinRash
HairLoss
Other
Fever
SmellLoss
TasteLoss
Occurence of smyptoms with LC
B
ME Symptom Co-occurrence Network
LC Symptom Co-occurrence Network
C
D
Frequency Symptom was reported vs
Proportion reporting Severe Impact of ME (n=284)
R = − 0.47, p = 0.0081
Frequency Symptom was reported vs
Proportion reporting Severe Impact of LC (n=77)
R = − 0.54, p = 0.0017
Proportion(%) Responding Severe/Very Severe Impact
Number of Times a Symptom is reported


Time until diagnosis with respect to 2021 NICE ME/CFS guidelines
%of patients in group
(Before: 2018-2021 After:2022-2024)
30
20
10
0
Less than 3 months.
3 – 6 months.
7 – 12 months.
1 – 2 years.
3 – 4 years.
5 – 6 years.
7 – 8 years.
9 – 10 years.
More than 10 years.
Prefer not to say
Time for Diagnosis
Diagnosis time relative
to 2021 NICE guidelines
after
before


Time for diagnosis by year (n=1722)
%patients per year
100
75
50
25
0
2019
2020
2021
2022
2023
Year
Time for Diagnosis
Less than 3 months.
3 – 6 months.
7 – 12 months.
1 – 2 years.
3 – 4 years.
5 – 6 years.
7 – 8 years.
9 – 10 years.
More than 10 years.
Prefer not to say

Appendix

Supplementary Table 1 - Demographic data from all respondents who have, or have a family member who has, a diagnosis or symptoms of ME/CFS/Long Covid.

	Under 18	18 - 29	30 - 39	40 - 49	50 - 59	60 - 69	70 - 79	80 or older	Didn't say
Female	80	469	827	1337	1719	1118	439	49	15
Male	27	59	107	198	295	249	126	14	2
Non-Binary/ Self-described	4	43	42	23	14	3	0	0	0

Supplementary Table 2: Age and gender of people with Long Covid and ME

		Under 18	18 - 29	30 - 39	40 - 49	50 - 59	60 - 69	70 - 79	80 or older	Didn't say
I have a close family member or friend that has been diagnosed with Long Covid	Female	9	1	4	6	4	5	1	0	0
	Male	5	1	0	2	2	2	2	1	0
	Non-binary	0	0	0	0	0	0	0	0	0
I have a close family member or friend that has been diagnosed with ME/CFS	Female	31	32	15	13	32	20	7	3	3
	Male	13	16	11	10	3	6	1	0	0
	Non-binary	2	3	0	0	0	0	0	0	0
I have a close family member or friend with symptoms of Long Covid but no diagnosis	Female	0	0	0	2	1	1	2	0	0
	Male	0	0	0	0	1	2	0	0	0
	Non-binary	0	0	0	0	0	0	0	0	0
I have a close family member or friend with symptoms of ME/CFS but no diagnosis	Female	2	0	0	1	4	4	0	1	0
	Male	0	1	0	0	0	1	1	0	0
	Non-binary	0	0	0	0	0	0	0	0	0
I have symptoms and a diagnosis of Long Covid	Female	7	27	80	150	179	74	17	3	0
	Male	2	3	14	29	37	23	9	0	0
	Non-binary	0	2	2	4	2	0	0	0	0
I have symptoms and a diagnosis of ME/CFS	Female	27	378	685	1109	1419	974	391	41	12
	Male	6	35	76	145	233	203	104	11	2
	Non-binary	2	32	36	19	12	3	0	0	0
I think I have Long Covid symptoms but have not been diagnosed	Female	1	3	7	11	16	7	12	0	0
	Male	1	0	1	1	3	6	3	2	0
	Non-binary	0	0	1	0	0	0	0	0	0
I think I have ME/CFS symptoms but have not been diagnosed	Female	3	28	36	45	64	33	9	1	0
	Male	0	3	5	11	16	6	6	0	0
	Non-binary	0	6	3	0	0	0	0	0	0

Supplementary Table 3: Ethnicity

ETHNICITY	**Number**
English/Welsh/Scottish/Northern Irish/British	6574
ANY OTHER WHITE BACKGROUND	306
IRISH	89
WOULD RATHER NOT SAY	78
ANY OTHER MIXED/MULTIPLE ETHNIC BACKGROUND	40
WHITE AND ASIAN	36
WHITE AND BLACK CARIBBEAN	34
ANY OTHER ETHNIC GROUP	33
INDIAN	31
(BLANK)	24
CARIBBEAN	9
PAKISTANI	8
ANY OTHER ASIAN BACKGROUND	8
ANY OTHER BLACK/AFRICAN/CARIBBEAN BACKGROUND	7
AFRICAN	7
WHITE AND BLACK AFRICAN	6
CHINESE	6
ARAB	3
BANGLADESHI	3
GYPSY OR IRISH TRAVELLER	1
GRAND TOTAL	**7303**

Supplementary Table 4: Time of Diagnosis

Time of diagnosis for ME/CFS	**Numbers**	**Percentage**
Less than 3 months.	388	5.15
7 – 12 months.	1419	18.84
1 – 2 years.	1664	22.1
3 – 4 years.	883	11.72
3 – 6 months.	1240	16.47
5 – 6 years.	461	6.12
7 – 8 years.	249	3.31
9 – 10 years.	201	2.67
More than 10 years.	975	12.95
Prefer not to say	51	0.68
Grand Total	**7531**	**100**

Supplementary Table 5 - Responses to the question 'What is your overall experience of the NHS in regard to having Long Covid, and/or ME/CFS?'

		Very Poor	Poor	Mixed	Good	Excellent	Don't know
Diagnosed Long COVID	Count	158	120	258	84	19	8
	%	22.13	16.81	36.13	11.76	2.66	1.12
Diagnosed ME/CFS	Count	2157	1175	1631	338	89	34
	%	33.76	18.39	25.52	5.29	1.39	0.53

Supplementary Table 6 - Responses to the question 'When did a Specialist last see you?'

Condition	**Timeframe**	**Count**	**Percentage (%)**
Long COVID	In the last month	84	23.66
	2-6 months ago	133	37.46
	7-11 months ago	46	12.96
	1-2 years ago	60	16.90
	3-4 years ago	5	1.41
	5 years ago or longer	0	0.00
	I haven't been seen	24	6.76
	Don't know	3	0.85

Supplementary Table 7 - Responses to the question 'How do you manage your symptoms?' Count and percentages of all respondents within the group.

Symptom management method	Count	Long COVID			ME/CFS		
		Diagnosed	Undiagnosed	Total	Diagnosed	Undiagnosed	Total
Cognitive behavioural therapy (to help me cope)	Count	93	5	98	855	29	884
	%	13.7	6.5	12.9	14.0	10.3	13.8
Counselling (to help me cope)	Count	171	16	187	1263	39	1302
	%	25.1	20.8	24.7	20.7	13.9	20.4
Occupational therapy	Count	117	2	119	512	10	522
	%	17.2	2.6	15.7	8.4	3.6	8.2
Graded Exercise Therapy	Count	23	2	25	173	4	177
	%	3.4	2.6	3.3	2.8	1.4	2.8
Pulmonary Rehabilitation	Count	29	3	32	21	3	24
	%	4.3	3.9	4.2	0.3	1.1	0.4
Physiotherapy	Count	104	5	109	564	23	587
	%	15.3	6.5	14.4	9.2	8.2	9.2

I received medication from a GP (prescription)	Count	316	27	343	2491	63	2554
	%	46.4	35.1	45.3	40.7	22.4	39.9
I've been self-treating with over-the-counter medications (from a pharmacy)	Count	183	18	201	1088	63	1151
	%	26.9	23.4	26.5	17.8	22.4	18.0
I've been taking vitamins or supplements	Count	434	43	477	3740	162	3902
	%	63.7	55.8	62.9	61.2	57.7	61.0
I self-manage without the use of medications	Count	116	19	135	1379	64	1443
	%	17.0	24.7	17.8	22.5	22.8	22.6
I've made changes to my diet	Count	312	27	339	2757	120	2877
	%	45.8	35.1	44.7	45.1	42.7	45.0
I try to balance activities with rest	Count	465	58	523	4382	184	4566
	%	68.3	75.3	69.0	71.6	65.5	71.4
I rest and sleep a lot more than before	Count	550	63	613	4678	221	4899
	%	80.8	81.8	80.9	76.5	78.6	76.6
I've had to reduce all activities	Count	528	57	585	4908	227	5135
	%	77.5	74.0	77.2	80.2	80.8	80.3
I've had to reorganise my life and take things a lot easier	Count	567	55	622	4939	223	5162
	%	83.3	71.4	82.1	80.8	79.4	80.7
Self-management approaches (energy management, pacing etc.)	Count	433	39	472	3958	139	4097
	%	63.6	50.6	62.3	64.7	49.5	64.0
Alternative or complementary approaches (massage, reiki, homeopathy etc.)	Count	174	12	186	1595	55	1650
	%	25.6	15.6	24.5	26.1	19.6	25.8
I cope as best I can on my own	Count	346	53	399	3342	153	3495
	%	50.8	68.8	52.6	54.6	54.4	54.6
I've been too sick to be able to try anything	Count	65	5	70	787	23	810
	%	9.5	6.5	9.2	12.9	8.2	12.7
None of the above	Count	2	0	2	7	1	8
	%	0.3	0.0	0.3	0.1	0.4	0.1
Other(please specify)	Count	114	3	117	935	26	961
	%	16.7	3.9	15.4	15.3	9.3	15.0
Prefer not to say	Count	0	0	0	9	0	9
	%	0.0	0.0	0.0	0.1	0.0	0.1
	Count	681	77	758	6116	281	6397

The ME Association
Count ME In Survey
18 May 2023
Final: Version 9

Introduction on first page of survey (longer intro on MEA website launch page):

Thank you for taking the time to complete the survey today for the ME Association. It will take around 10 minutes, and if you aren't able to complete it all in one go, your progress will automatically save and you can return later for up to 3 days.

This survey is run by One Minute to Midnight, a market research agency, on behalf of the ME Association. All your answers will be treated in complete confidence in accordance with the Market Research Society Code of Conduct and GDPR. We will not be asking you for any personally identifiable information.

Completing this survey will enable the ME Association to:

1. Inform more people about ME/CFS and Long Covid, help them obtain an accurate diagnosis if needed, and find the right support to improve their life quality.
2. Produce an independent report that will raise awareness and help us improve the standard of healthcare by working with the NHS and social care services.

ME = Myalgic Encephalopathy or Encephalomyelitis.
CFS = Chronic Fatigue Syndrome
Long Covid = Post-Covid Syndrome

CLICK HERE TO START THE SURVEY

SECTION A: SCREENING

Q1. Do you, or any of your close friends or family currently have a diagnosis of any of the following? Or do you think you or a close friend or family member might have symptoms of any of the following?
Please tick all that apply

1. ME / CFS or Long Covid
2. Diabetes
3. Alzheimer's
4. Rheumatoid Arthritis
5. Multiple Sclerosis
6. Cancer
7. None of the above

Q2. Which one of these most applies to you?

1. I have symptoms and a diagnosis of ME/CFS
2. I have symptoms and a diagnosis of Long Covid
3. I think I have ME/CFS symptoms but have not been diagnosed
4. I think I have Long Covid symptoms but have not been diagnosed
5. I had symptoms or a diagnosis of ME/CFS but have now recovered
6. I had symptoms or a diagnosis of Long Covid but have now recovered
7. I have a close family member or friend that has been diagnosed with ME/CFS
8. I have a close family member or friend that has been diagnosed with Long Covid
9. I have a close family member or friend with symptoms of ME/CFS but no diagnosis
10. I have a close family member or friend with symptoms of Long Covid but no diagnosis
11. None of these

ASK IF FRIEND/FAMILY HAS ME/CFS/LC OR SYMPTOMS AND NOT THEMSELVES (Q2 = CODE 7, 8, 9 or 10)
Q3. This survey will ask about the experiences of people with (or who might have) ME/CFS or Long Covid. Do you have the permission of the friend or family member to complete this survey on their behalf? If not, please send them the survey or come back and complete the survey with them.

1. Yes
2. No

SHOW IF YES AT Q3:
Please answer the rest of the survey from the perspective of your friend or family member.

RESPONDENT TYPE:

- ME / CFS: Q2 = 1 or 7
- Long Covid: Q2 = 2 or 8
- Undiagnosed: Q2 = 3, 4, 9 or 10

UNDIAGNOSED ROUTE:

UNDIAGNOSED ONLY
Q4. Have you consistently experienced any of these symptoms for at least 3 months?
Please tick all that apply

1. Debilitating Fatigue / Exhaustion: Symptoms are worsened by activity and do not get better with rest.
2. Post-Exertional Malaise: Symptoms are made worse after activity, the impact is often delayed, is disproportionate to the activity and has a long recovery time.
3. Unrefreshing sleep or sleep disturbance: This may include feeling exhausted, flu-like, and stiff on waking, broken or shallow sleep, altered sleep patterns, or needing to sleep too much.
4. 'Brain Fog' or cognitive difficulties: This may include problems finding words or numbers, difficulty speaking, slowed responses, short-term memory problems, and difficulty concentrating.

[ME/CFS & LC Additional Symptoms]

5. Alcohol intolerance.

6. Difficulty maintaining an upright position.
7. Dizziness.
8. Excessive sweating when asleep.
9. Faintness.
10. Headache.
11. Increased sensitivity to hot and cold temperatures.
12. Increased sensitivity to light and noise.
13. Irritable-bowel-type symptoms.
14. Muscle twitches or jerks.
15. Nausea.
16. Pain in muscles, joints, or nerves.
17. Heart palpitations.
18. Flu-like symptoms (persistent).
19. Rapid rise in heart rate on standing up.

[LC Additional Symptoms]

20. Breathlessness.
21. Chest pains.
22. Cough.
23. Earache.
24. Fever.
25. Loss of taste.
26. Loss of smell.
27. Hair loss.
28. Ringing in the ears.
29. Skin rashes.
30. Sore throat.
31. Other (please specify): [ANCHOR] [OPEN END]
32. None of the above: [ANCHOR] [EXCLUSIVE] [**CLOSE**]
33. Prefer not to say: [ANCHOR] [EXCLUSIVE] [**CLOSE**]

ASK IF UNDIAGNOSED

Q5. You said you experience:

- Debilitating Fatigue / Exhaustion
- Post-Exertional Malaise
- Unrefreshing Sleep or Sleep Disturbance
- Brain Fog or cognitive difficulties

For how long have you experienced all of these symptoms?

1. Less than 6 months
2. 6-11 months
3. 1 – 3 years
4. 4 – 5 years
5. 6 – 7 years
6. 8 – 9 years
7. 10 years +
8. Don't know

ASK IF UNDIAGNOSED

Q6. What has prevented you from getting a diagnosis?
Please tick all that apply

1. I wasn't sure if my symptoms related to anything specific
2. I wasn't sure if my symptoms were related to ME/CFS or Long Covid
3. I wasn't able to get an appointment with a GP
4. I've been too unwell and can't get a GP to visit me at home
5. I am waiting for an appointment with a GP
6. I am waiting for a referral to a consultant
7. I am waiting for a referral to an ME/CFS specialist service
8. I am waiting for a referral to a Long Covid clinic
9. The GP didn't think my symptoms were related to ME/CFS or Long Covid
10. The GP didn't mention ME/CFS or Long Covid
11. The GP didn't believe ME/CFS or Long Covid were 'real'
12. The GP did not want to make a referral to a specialist
13. There are no ME/CFS specialist services in my area
14. There are no Long Covid clinics in my area
15. I don't think my symptoms are severe enough

16. I don't think a GP or consultant can help
17. I don't think an ME/CFS specialist service or Long Covid clinic can help
18. I have delayed making an appointment because I don't want to cause more work for the NHS
19. I will be making a GP appointment and seeking a diagnosis once I complete this survey
20. Other (please specify): [ANCHOR] [OPEN END]
21. None of the above: [ANCHOR] [EXCLUSIVE]
22. Prefer not to say: [ANCHOR] [EXCLUSIVE]

ASK IF WAITING FOR APPOINTMENT (Q10 = 5, 6, 7 OR 8)

Q7. For how long have you been waiting for an appointment or referral?

1. Less than a month
2. 1 – 3 months
3. 4 – 6 months
4. 7 – 12 months
5. 1-2 years
6. More than 2 years
7. Don't know

ASK ALL

Q8. SHOW TO ME/CFS: To what extent does ME / CFS impact your life today?
SHOW TO LC: To what extent does Long Covid impact your life today?
Please choose the one option that applies to you the most

1. **No Impact**
   You experience no problems with personal care or daily living. Your physical and cognitive abilities have been restored either completely or to a significant extent. You experience no symptoms at rest or after exertion and have not done so for 3 months or more. You feel capable of returning to full-time work or education and to leisure and social activities.
2. **Mild Impact**
   You are able to care for yourself and do some light domestic tasks (sometimes needing support), but you experience difficulties with mobility. You might still be able to work or go to school, college or university, but you have probably stopped all leisure and social activities. You often need reduced hours, take days off and use the weekend to cope with the rest of the week.
3. **Moderate Impact**
   You have reduced mobility and are restricted in all activities of daily living. You might have peaks and troughs in the range and severity of symptoms and your ability to initiate and complete activities. You have probably had to stop going work or school, college or university. You are likely to need rest periods, often in the afternoon. Your sleep at night is generally poor quality and disturbed [LC: and you may have difficulty breathing properly].
4. **Severe Impact**
   You are unable to do any activity for yourself or can carry out only minimal daily tasks (such as face washing or cleaning teeth). You have severe cognitive difficulties and may depend on a wheelchair for mobility. You are often unable to leave the house or have a severe and prolonged after-effect if you do. You may spend most of your time in bed [ME/CFS: and are often extremely sensitive to light and sound. / LC: and are likely to experience breathing problems and with heart function.]
5. **Very severe Impact**
   You are unable to leave your bed and are wholly dependent on the care and support of others. Physical or cognitive activities will be extremely limited. You need help with personal hygiene and eating [ME/CFS: and are very sensitive to light, noise, and touch / LC: You will experience severe difficulty breathing and with heart function]. You might not be able to swallow, and you may need to be tube-fed. You will be very weak and might be unable to communicate verbally.

Q9. Which of the following have you used to find help and support?
Please tick all that apply

1. An NHS counsellor or psychologist
2. An NHS GP
3. An NHS consultant
4. A pharmacist
5. Social care services
6. A private GP or consultant
7. A private counsellor or psychologist
8. The ME Association
9. Another UK charity
10. A non-UK charity

11. I searched online to get information
12. Family and friends
13. Other people with similar symptoms
14. I joined a local support group
15. I joined an online support group
16. Other (please specify): [ANCHOR] [OPEN END]
17. None of the above: [ANCHOR] [EXCLUSIVE]
18. Prefer not to say: [ANCHOR] [EXCLUSIVE]

ASK ALL
Q10. How do you manage your symptoms?
Please tick all that apply

1. I've had to reorganise my life and take things a lot easier. PIPE
2. I've had to reduce all activities. PIPE
3. I rest and sleep a lot more than before. PIPE
4. I try to balance activities with rest. PIPE
5. I've been too sick to be able to try anything.
6. I cope as best I can on my own.
7. I've been self-treating with over-the-counter medications (from a pharmacy). PIPE
8. I received medication from a GP (prescription). PIPE
9. I self-manage without the use of medications. PIPE
10. Physiotherapy PIPE
11. Occupational therapy PIPE
12. Graded Exercise Therapy PIPE
13. Counselling (to help me cope). PIPE
14. Cognitive behavioural therapy (to help me cope). PIPE
15. I've been using alternative or complementary approaches (massage, reiki, homeopathy, etc.). PIPE
16. I've been using self-management approaches (energy management, pacing, etc.). PIPE
17. I've been taking vitamins or supplements. PIPE
18. I've made changes to my diet. PIPE
19. Pulmonary rehabilitation PIPE
20. Other (please specify): [ANCHOR] [OPEN END] PIPE
21. None of the above: [ANCHOR] [EXCLUSIVE]
22. Prefer not to say: [ANCHOR] [EXCLUSIVE]

Q11. How helpful have each of these approaches been at helping you find relief from your symptoms?

1. Very Helpful.
2. Helpful.
3. Hard to tell.
4. Unhelpful.
5. Very unhelpful.
6. Prefer not to say: [ANCHOR] [EXCLUSIVE]

ME/CFS ROUTES: (Text substitutions used where appropriate)

ASK IF ME/CFS OR LONG COVID
Q4. How long did it take to receive a diagnosis of [ME/CFS / Long Covid] after you first noticed symptoms and informed a GP?

SINGLE CODE

1. Less than 3 months.
2. 3 – 6 months.
3. 7 – 12 months.
4. 1 – 2 years.
5. 3 – 4 years.
6. 5 – 6 years.
7. 7 – 8 years.
8. 9 – 10 years.
9. More than 10 years.
10. Prefer not to say

ASK IF ME/CFS OR LONG COVID

Q5. When were you diagnosed with [ME/CFS / Long Covid]?
Year:

ASK ME/CFS

Q6. Have you been diagnosed with any of the following conditions in addition to ME / CFS?
Please tick all that apply

1. Allergies.
2. Anxiety.
3. Chemical sensitivities.
4. Depression.
5. Diabetes (type 1).
6. Diabetes (type 2).
7. Endometriosis.
8. Fibromyalgia.
9. Hypermobility syndromes.
10. Incontinence.
11. Insomnia.
12. Interstitial cystitis.
13. Irritable bowel syndrome (IBS).
14. Mast Cell Activation Syndrome (MCAS).
15. Migraine.
16. Orthostatic Intolerance.
17. Postural Orthostatic Tachycardia Syndrome (PoTS).
18. Other (please specify):
19. None of the above:
20. Prefer not to say

ASK LONG COVID

Q7. Have you been diagnosed with any of the following conditions in addition to Long Covid?
Please tick all that apply

MULTICODE

1. Allergies.
2. Anxiety.
3. Arrhythmia.
4. Asthma.
5. Depression.
6. Diabetes (type 1).
7. Diabetes (type 2).
8. Eczema.
9. Endometriosis.
10. Heart failure.
11. Hypertension.
12. Inflammatory bowel disease (IBD).
13. Insomnia.
14. Incontinence.
15. Irritable bowel syndrome (IBS).
16. Migraine.
17. Myocardial Infarction.
18. Myositis.
19. Orthostatic Intolerance.
20. Postural Orthostatic Tachycardia Syndrome (PoTS).
21. Pulmonary Fibrosis.
22. Renal damage.
23. Sexual dysfunction.
24. Other (please specify):
25. None of the above:
26. Prefer not to say:

ASK ALL

Q8. SHOW TO ME/CFS: To what extent does ME / CFS impact your life today?
SHOW TO LC: To what extent does Long Covid impact your life today?
Please choose the one option that applies to you the most

1. **No Impact**
   You experience no problems with personal care or daily living. Your physical and cognitive abilities have been restored either completely or to a significant extent. You experience no symptoms at rest or after exertion and have not done so for 3 months or more. You feel capable of returning to full-time work or education and to leisure and social activities.
2. **Mild Impact**
   You are able to care for yourself and do some light domestic tasks (sometimes needing support), but you experience difficulties with mobility. You might still be able to work or go to school, college or university, but you have probably stopped all leisure and social activities. You often need reduced hours, take days off and use the weekend to cope with the rest of the week.
3. **Moderate Impact**
   You have reduced mobility and are restricted in all activities of daily living. You might have peaks and troughs in the range and severity of symptoms and your ability to initiate and complete activities. You have probably had to stop going work or school, college or university. You are likely to need rest periods, often in the afternoon. Your sleep at night is generally poor quality and disturbed [LC: and you may have difficulty breathing properly].
4. **Severe Impact**
   You are unable to do any activity for yourself or can carry out only minimal daily tasks (such as face washing or cleaning teeth). You have severe cognitive difficulties and may depend on a wheelchair for mobility. You are often unable to leave the house or have a severe and prolonged after-effect if you do. You may spend most of your time in bed [ME/CFS: and are often extremely sensitive to light and sound. / LC: and are likely to experience breathing problems and with heart function.]
5. **Very severe Impact**
   You are unable to leave your bed and are wholly dependent on the care and support of others. Physical or cognitive activities will be extremely limited. You need help with personal hygiene and eating [ME/CFS: and are very sensitive to light, noise, and touch / LC: You will experience severe difficulty breathing and with heart function]. You might not be able to swallow, and you may need to be tube-fed. You will be very weak and might be unable to communicate verbally.

Q9. Which of the following have you used to find help and support for your symptoms or diagnosis?
Please tick all that apply

1. A NHS counsellor or psychologist
2. An NHS GP
3. An NHS consultant
4. A hospital-based ME/CFS specialist service – DIAGNOSED ME/CFS ONLY
5. A hospital based Long Covid clinic – DIAGNOSED LC ONLY
6. A pharmacist
7. Social care services
8. Private GP or consultant
9. A private counsellor or psychologist
10. The ME Association
11. Another UK charity
12. A non-UK charity
13. I searched online to get information
14. Family and friends
15. Other people with similar symptoms
16. I joined a local support group
17. I joined an online support group
18. Other (please specify): [ANCHOR] [OPEN END]
19. None of the above: [ANCHOR] [EXCLUSIVE]
20. Prefer not to say: [ANCHOR] [EXCLUSIVE]

ASK IF HAS USED NHS HELP
Q10a. What help have you received from the NHS in regard to ME/CFS or Long Covid in the last 2 years?
Please tick all that apply

MULTICODE

1. An assessment from a GP.
2. An assessment from a consultant.
3. An assessment from an [ME/CFS specialist service / Long Covid clinic].
4. Information and support from a GP about learning how to live with [ME/CFS / Long Covid].

5. Information and support from a consultant about learning how to live with [ME/CFS / Long Covid].
6. Information and support from an [ME/CFS specialist service / Long Covid clinic] about learning how to live with the condition.
7. A diagnosis from a GP
8. None of the above:
9. Prefer not to say:

ASK IF HAS NOT USED NHS HELP (Q13 = NOT CODE ANY OF 1-5)

Q10b. Why have you not received help from the NHS in regard to ME/CFS or Long Covid in the last 2 years?

MULTICODE

1. I didn't know ME/CFS specialist services could help but will ask a GP after completing this survey.
2. I have not needed to use the NHS
3. I have not used an [ME/CFS specialist service / Long Covid clinic] because I didn't think they could help me.
4. I have not used an [ME/CFS specialist service / Long Covid clic] because there isn't one in my area.
5. I have not used the NHS. I paid for private healthcare.
6. I have not used the NHS. I don't believe they can help me.
7. None of the above: [ANCHOR][EXCLUSIVE]
8. Prefer not to say: [ANCHOR][EXCLUSIVE]

ASK IF HAS USED NHS HELP (Q13 = CODE ANY OF 1-5)

Q11. What is your overall experience of the NHS in regard to having ME/CFS or Long Covid?

1. Very poor
2. Poor
3. Mixed
4. Good
5. Excellent
6. Don't know

ASK IF CODE 1-5 AT Q15

Q12. Why do you say your experience of the NHS is [Q15 ANSWER]?
NON-MANDATORY OPEN END

ASK IF ME/CFS OR LONG COVID AND HAS USED SOCIAL CARE SERVICES (Q13 = 6)

Q13. What help have you received from social care services in regard to ME/CFS?
Please tick all that apply

1. I've had a care needs assessment that was successful.
2. I've had a care needs assessment that was unsuccessful.
3. I've not applied for an assessment but need social care support.
4. I am waiting to receive a care needs assessment.
5. I am waiting on the outcome of a care needs assessment.
6. I receive a personal budget and employ a carer.
7. I receive a personal budget and my local authority provide a carer.
8. I've had changes made to my home (e.g., grab rails, walk-in shower, etc.).
9. I need changes made to my home but haven't been offered any.
10. I've not needed changes made to my home.
11. I've been provided with equipment (e.g., wheelchair, personal alarm, etc.).
12. I need equipment but haven't been offered any.
13. I've not needed any equipment.
14. I've been moved to sheltered accommodation.
15. I've not been moved to sheltered accommodation, but I need to be.
16. I haven't needed support from social care services.
17. I didn't think I was eligible for social care but will contact my local authority after completing this survey.
18. None of the above:
19. Prefer not to say:

ASK IF ME/CFS OR LONG COVID AND HAS USED SOCIAL CARE SERVICES (Q13 = 6)
Q14. What is your overall experience of social care services in regard to having [ME/CFS / Long Covid]?

1. Very poor
2. Poor
3. Mixed
4. Good
5. Excellent
6. Don't know

ASK IF CODE 1-5 AT Q18
Q15. Why do you say your experience of social care services is..

NON-MANDATORY OPEN END

ASK IF ME/CFS OR LONG COVID AND HAS USED A SPECIALIST SERVICE / CLINIC (Q13 = 4)
Q16. You said you've used an [ME/CFS specialist service / Long Covid clinic]. Which of these apply to you in terms of the effect the service had on your health and wellbeing?
Tick all that apply

1. I received a medical assessment.
2. I received a diagnosis.
3. I felt my experiences were validated and I was made comfortable
4. I benefited from the information, support and management recommendations.
5. The healthcare professionals at the service were knowledgeable and understanding.
6. I felt the specialist service met my expectations.
7. I felt the service was able to tailor recommendations to meet my needs.
8. I felt the number of appointments with the service were sufficient
9. I was able to return to the service when needed e.g., when I relapsed.
10. I was able to access the service remotely when needed.
11. I benefited from the support when severely or very severely affected.
12. I helped to create a care and support plan which was shared with my GP.
13. None of these
14. Other. Please specify [ ]

ASK IF ME/CFS OR LONG COVID AND HAS USED A SPECIALIST SERVICE / CLINIC (Q13 = 4)
Q17. When were you last seen by [an ME/CFS specialist service / a Long Covid clinic]?

1. In the last month
2. 2 – 6 months ago
3. 7 – 11 months ago
4. 1 – 2 years ago
5. 3 – 4 years ago
6. 5 years ago or longer
7. I haven't been seen
8. Don't know

ASK IF ME/CFS OR LONG COVID AND HAS USED A SPECIALIST SERVICE / CLINIC (Q13 = 4)
Q18. What is the name [ME/CFS specialist service / Long Covid clinic] you have used?

NON-MANDATORY OPEN END

ASK IF ME/CFS OR LONG COVID AND HAS USED A SPECIALIST SERVICE / CLINIC (Q13 = 4)
Q19. What was your overall experience of this specialist service / Long Covid clinic?

1. Very poor
2. Poor
3. Mixed

4. Good
5. Excellent
6. Don't know

ASK IF CODE 1-5 AT Q23
Q20. Why do you say your experience of the specialist service is [Q23 ANSWER]?
NON-MANDATORY OPEN END

ASK ALL
Q21. How do you manage your symptoms?
Please tick all that apply

1. I've had to reorganise my life and take things a lot easier. PIPE
2. I've had to reduce all activities. PIPE
3. I rest and sleep a lot more than before. PIPE
4. I try to balance activities with rest. PIPE
5. I've been too sick to be able to try anything.
6. I cope as best I can on my own.
7. I've been self-treating with over-the-counter medications (from a pharmacy). PIPE
8. I received medication from a GP (prescription). PIPE
9. I self-manage without the use of medications. PIPE
10. Physiotherapy PIPE
11. Occupational therapy PIPE
12. Graded Exercise Therapy PIPE
13. Counselling (to help me cope). PIPE
14. Cognitive behavioural therapy (to help me cope). PIPE
15. I've been using alternative or complementary approaches (massage, reiki, homeopathy, etc.). PIPE
16. I've been using self-management approaches (energy management, pacing, etc.). PIPE
17. I've been taking vitamins or supplements. PIPE
18. I've made changes to my diet. PIPE
19. Pulmonary rehabilitation PIPE
20. Other (please specify):
21. None of the above:
22. Prefer not to say:

Q22. How helpful have each of these approaches been at helping you find relief from your symptoms?

7. Very Helpful.
8. Helpful.
9. Hard to tell.
10. Unhelpful.
11. Very unhelpful.
12. Prefer not to say: [ANCHOR] [EXCLUSIVE]

ASK ME/CFS OR LONG COVID
Q23. What improvements would you most like to see to the NHS that could improve your quality of life with regard to [ME/CFS / Long Covid]?

NON-MANDATORY OPEN END

ASK IF ME/CFS OR LONG COVID
Q24. **ME CFS:** A new NICE Guideline on ME/CFS was published in October 2021. This tells doctors how to treat / manage ME / CFS. Are you aware of this guideline?
Long Covid: The NICE Rapid Guideline on Long Covid was last updated in November 2021. This tells doctors how to treat / manage Long Covid. Are you aware of this guideline?

SINGLE CODE

1. Yes
2. No
3. Don't know

ASK IF AWARE OF GUIDELINE (Q27 = 1)
Q25. Do you think the NICE guideline's recommendations have had a positive effect on the healthcare that you have received?

1. Yes. It's made a big difference.
2. Yes. It's made some difference.
3. I don't know. I haven't used the NHS since it was published.
4. I don't know. I haven't read the Guideline.
5. No. I don't think the NHS is aware of the Guideline.
6. No. I haven't noticed a difference.
7. Don't know

ASK IF AWARE OF GUIDELINE (Q27 = 1)
Q26. Is there anything you'd like to tell us about your opinion of the NICE guideline?

NON-MANDATORY OPEN END

SECTION E: DEMOGRAPHICS (ASK ALL):

SHOW TO ALL: Thank you, for all your answers so far. The last few questions are just to find out a bit more about who has completed the survey.

ASK ALL
Q27. How old are you?

1. Under 18
2. 18 - 29
3. 30 – 39
4. 40 – 49
5. 50 – 59
6. 60 – 69
7. 70 – 79
8. 80 or older
9. Would rather not say

Q28. Which of the following best describes your gender?

1. Female
2. Male
3. Non-binary or prefer to self-describe
4. Would rather not say

Q29. Where do you live?

1. North East England
2. North West England
3. Yorkshire and the Humber
4. East Midlands
5. West Midlands
6. East of England
7. London
8. South East England
9. Southwest England
10. Wales
11. Northern Ireland
12. Scotland
13. Channel Islands

14. Isle of Man
15. Outside of the UK
16. Prefer not to say

Q30. In which county do you live?

[IF NORTH EAST ENGLAND]
1. Northumberland
2. Tyne and Wear
3. County Durham
4. Teesside

[IF NORTH WEST ENGLAND]
1. Cumbria
2. Lancashire
3. Greater Manchester
4. Merseyside
5. Cheshire

[IF YORKSHIRE AND THE HUMBER]
1. North Yorkshire
2. South Yorkshire
3. West Yorkshire
4. East Riding of Yorkshire
5. North Lincolnshire
6. North East Lincolnshire

[IF EAST MIDLANDS]
1. Derbyshire
2. Leicestershire
3. Lincolnshire
4. Northamptonshire
5. Nottinghamshire
6. Rutland

[IF WEST MIDLANDS]
1. Herefordshire
2. Shropshire
3. Staffordshire
4. Warwickshire
5. West Midlands
6. Worcestershire

[IF EAST OF ENGLAND]
1. Bedfordshire
2. Cambridgeshire
3. Essex
4. Hertfordshire
5. Norfolk
6. Suffolk

[IF SOUTH EAST ENGLAND]
1. Berkshire
2. Buckinghamshire
3. East Sussex
4. Hampshire
5. Isle of Wight
6. Kent
7. Oxfordshire
8. Surrey
9. West Sussex

[IF SOUTH WEST ENGLAND]
1. Bristol
2. Cornwall
3. Devon
4. Dorset
5. Gloucestershire
6. Somerset

7. Wiltshire

[IF WALES]
1. Blaenau Gwent
2. Bridgend
3. Caerphilly
4. Cardiff
5. Carmarthenshire
6. Ceredigion
7. Conwy
8. Denbighshire
9. Flintshire
10. Gwynedd
11. Isle of Anglesey
12. Merthyr Tydfil
13. Monmouthshire
14. Neath Port Talbot
15. Newport
16. Pembrokeshire
17. Powys
18. Rhondda Cynon Taf
19. Swansea
20. Torfaen
21. Vale of Glamorgan
22. Wrexham

[IF NORTHERN IRELAND]
1. Antrim
2. Armagh
3. Down
4. Fermanagh
5. Londonderry
6. Tyrone

[IF SCOTLAND]
1. Aberdeenshire
2. Angus
3. Argyll and Bute
4. Clackmannanshire
5. Dumfries and Galloway
6. Dundee
7. East Ayrshire
8. East Dunbartonshire
9. East Lothian
10. East Renfrewshire
11. Edinburgh
12. Falkirk
13. Fife
14. Glasgow
15. Highland
16. Inverclyde
17. Midlothian
18. Moray
19. Na h-Eileanan Siar (Western Isles)
20. North Ayrshire
21. North Lanarkshire
22. Orkney Islands
23. Perth and Kinross
24. Renfrewshire
25. Scottish Borders
26. Shetland Islands
27. South Ayrshire
28. South Lanarkshire
29. Stirling
30. West Dunbartonshire
31. West Lothian

[IF CHANNEL ISLANDS]
1. Jersey
2. Guernsey

3. Alderney
4. Sark

Q31. How would you describe your ethnicity?

White
1. English/Welsh/Scottish/Northern Irish/British
2. Irish
3. Gypsy or Irish Traveller
4. Any other White background

Mixed/Multiple ethnic groups
5. White and Black Caribbean
6. White and Black African
7. White and Asian
8. Any other Mixed/Multiple ethnic background

Asian/Asian British
9. Indian
10. Pakistani
11. Bangladeshi
12. Chinese
13. Any other Asian background

Black/ African/Caribbean/Black British
14. African
15. Caribbean
16. Any other Black/African/Caribbean background

Other ethnic group
17. Arab
18. Any other ethnic group